AN EXPLORATION OF THE PSYCHOLOGICAL AND EMOTIONAL NEEDS OF PREGNANT WOMEN WHO HAVE UNDERGONE FEMALE GENITAL MUTILATION (FGM)

January 2015

Victoria Higham
200780864

Word Count
26,101

Supervised by:
Professor Pauline Slade
Dr Joanne Topping

Submitted in partial fulfilment of the Doctorate in Clinical Psychology, University of Liverpool

Table of Contents

Introduction

Introductory Chapter: Thesis Overview

This thesis consists of three chapters: a literature review, an empirical paper and a discussion chapter. This introduction provides an overview of each of chapter and how they link together. The main theme which runs throughout the thesis is Female Genital Mutilation (FGM), also known as female genital cutting or female circumcision. For some women, the term FGM is an appropriate description of their experience; however, for others FGM may be viewed offensively. Throughout the thesis and research process, the term FGM or circumcision was used interchangeably to describe women's experiences and to reflect women's own language preferences.

Chapter One consists of a literature review, synthesising the evidence of the psychological and emotional consequences of FGM. Research has generally focused on the physical consequences of FGM; more recently, however, the research has shifted focus to examine the psychological experiences of women with FGM. Berg, Denison, & Fretheim (2010) attempted to synthesise the evidence of the psychological consequences of FGM; however, the review was limited to include only quantitative studies. Given that much of the research with women with FGM is small scale and uses qualitative methodology, the Berg et al., (2010) review may be limited. Chapter One of the thesis attempted to address the limitation of the Berg et al. (2010) review by quality assessing and synthesising research utilising qualitative *and* quantitative methods to investigate the psychological and emotional consequences in women with FGM.

Similar to the wider FGM research, the evidence exploring the impact of FGM during pregnancy has focused on the physical complications. The physical complications of FGM can present additional complications in pregnancy and childbirth including the need for de-infibulation in pregnancy (re-opening the entrance of the vagina after Type III), difficulties in monitoring labour, bleeding and additional tears. Pregnancy is a crucial transition period for *all* women, requiring physical *and* psychological adjustment. Research suggested that women with FGM experience the physical and emotional body as linked (Jones, 2010); given the additional physical complications experienced by

women with FGM, pregnancy may be an even more pertinent time emotionally and psychologically. To date, however, there are no studies exploring the psychological and emotional experiences, at the time of being pregnant, with women with FGM in the United Kingdom (UK). Chapter Two is an empirical paper of a qualitative study addressing this gap.

The final chapter (Discussion) consists of three parts: An extended discussion synthesising the findings from Chapters One and Two, making reference to wider research and psychological theory; a lay person's summary, to disseminate the study's findings within the services where the research was undertaken; and a research proposal for a future study, to address the gaps in the literature, as highlighted in the first two chapters of the thesis.

Chapter One

Literature Review

The psychological and emotional consequences of Female Genital Mutilation (FGM): A review of the evidence.[1]

Victoria R. Higham

University of Liverpool

Professor Pauline Slade

University of Liverpool

Dr Joanne Topping

Liverpool Women's NHS Foundation Trust

Author Note

Victoria R. Higham, Department of Clinical Psychology, University of Liverpool; Professor Pauline Slade, Department of Clinical Psychology, University of Liverpool; Dr Joanne Topping, Department of Obstetrics, Liverpool Women's NHS Foundation Trust.

[1] To be submitted to: *International Journal of Nursing Studies* (word limit, 7000).

Abstract

Background: Female genital mutilation (FGM) describes procedures involving injury to, or partial or total removal of the external female genitalia for non-medical reasons. Previous research focused on the physical consequences of FGM. However, a growing body of evidence utilising various methodologies has investigated the psychological and emotional consequences of FGM. Objectives: The review adopted systematic methods to synthesise qualitative and quantitative research into psychological consequences to women with FGM. Methods: Systematic methods were used to select papers for inclusion; studies with witnesses to FGM, professionals and partners of women and studies not reporting psychological consequences were excluded. Thematic Synthesis collated the findings from the qualitative studies. Results: The review showed not all women developed psychological complications following FGM; positive beliefs about FGM, shared with the cultural group, may protect against psychological adversity. For some, FGM was associated with feelings of shame, loss and emotional distress, including increased rates of anxiety, depression and post-traumatic stress. Women may be more vulnerable at particular life stages. Conclusions: The review was the first to systematically synthesise findings from qualitative and quantitative research and supplemented understanding of the psychological and emotional consequences of FGM. Further research is needed to explore women's experiences during pertinent life stages e.g. marriage and pregnancy.

Keywords: Anxiety, depression, emotional, female circumcision, female genital cutting, female genital mutilation, mental health, psychological, review, thematic synthesis, well-being.

The psychological and emotional consequences of female genital mutilation (FGM): A review of the evidence.

FGM is used to describe procedures involving injury to, or partial or total removal of the external female genitalia, for non-medical reasons. The World Health Organisation (WHO) (2008) developed a classification system to identify the various types of FGM, ranging from pricking, piercing, incising, scraping and cauterisation of the genitalia ('Sunna' or Type I) to more extreme forms involve narrowing of the vaginal orifice with the creation of a covering seal by cutting and stitching the labia *minora* and/or the labia *majora*, with or without excision of the clitoris (infibulation or Type III). The types of procedures vary depending on the originating country or culture. FGM is often performed under unsanitary conditions, usually without anaesthetic, using everyday implements such as knifes, scissors, razor blades and glass.

FGM is pertinent to researchers and clinicians from health and mental health fields. The physical consequences of FGM are well documented and include: haemorrhaging; keloid scarring; chronic pain; reproductive, urinary and general infections; sexual difficulties; birthing complications and death (WHO, 2000). The procedure may also be perceived as traumatic (Berg, Denison, & Fretheim, 2010) and have emotional consequences. Berg et al. (2010) synthesised and quality assessed quantitative evidence of the psychological consequences of FGM; no definitive conclusions were made because of the quality of the research. This review was potentially limited as qualitative studies were excluded. The aim of the present review was to quality assess and synthesise the qualitative and quantitative data relating to the psychological and emotional consequences of FGM. The main review question was: What is the evidence for the psychological and emotional consequences of FGM?

Method

Inclusion Criteria

This review focused on papers, dissertations, or other sources of information (quantitative or qualitative primary data collected by the author/s) examining the psychological and/or emotional consequences of FGM. Studies were included if they collected data of women with direct personal experience with FGM and reported the findings in English. Studies with partners, professionals, or witnesses to FGM were excluded, as the review was interested in the personal consequences experienced by those who had undergone FGM. Studies were excluded if they examined the consequences of cosmetic procedures, accidental trauma to the female genitals or procedures performed for medical reasons.

Search Terms

Various terms are used to describe FGM; to ensure a broad search, the primary search terms used were 'female genital mutilation' OR 'female genital cutting' OR 'female circumcision'. Secondary search terms related to the psychological consequences of FGM; these were 'psych*'OR 'anxiety' OR 'depress*'OR 'stress' OR 'well-being'. Wildcard searches were employed for psych and depress to cover literature which employed keywords such as psychiatric and psychology/psychological/psyche/psychiatry or depression/depressed.

Search Strategy

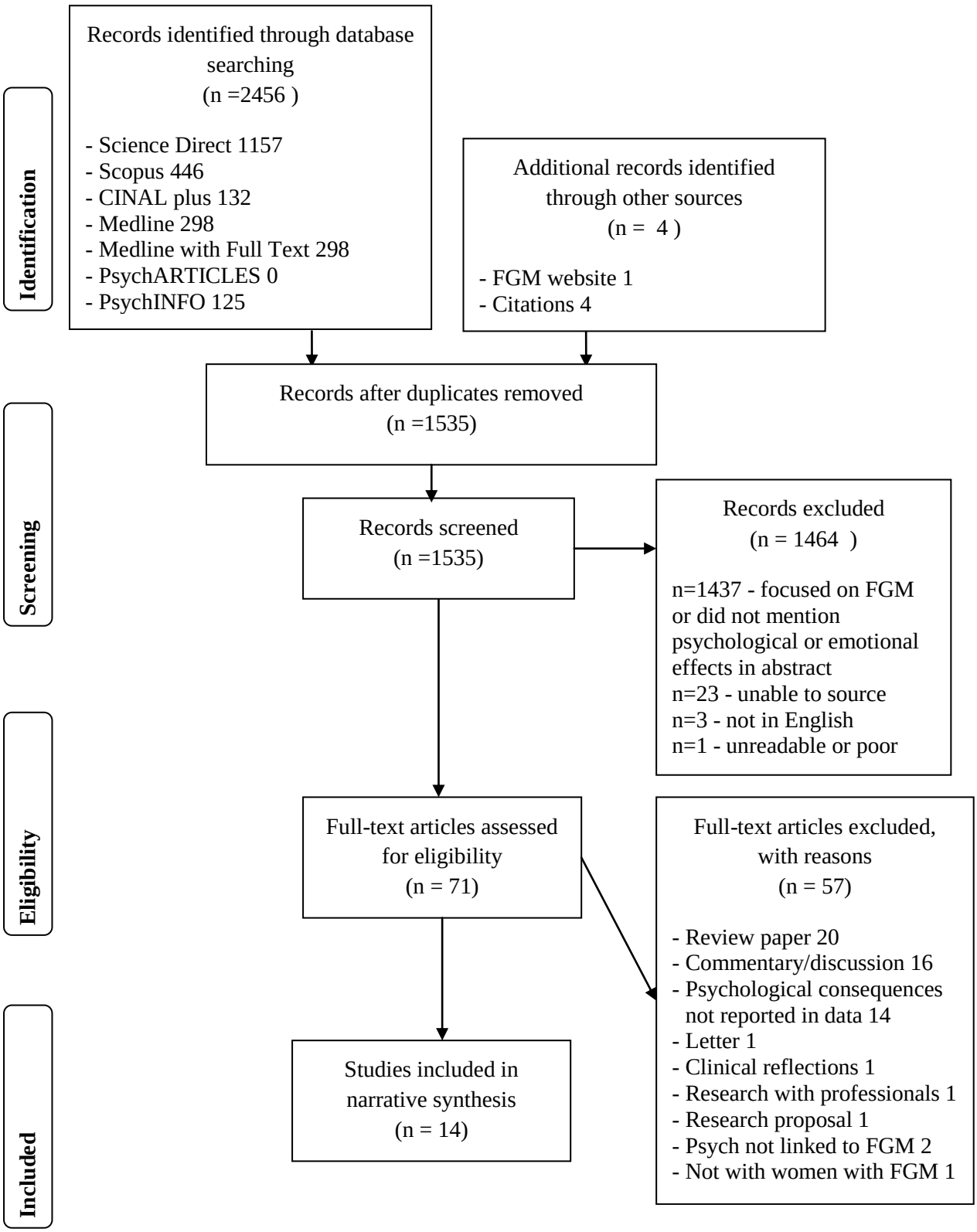
Databases searched included: CINAHL Plus, EBSCO, MEDLINE, MEDLINE with Full Text, PsycARTICLES, PsycINFO, Science Direct and Scopus. Alerts were set up on all databases to include newly published research. DISCOVER was used to search for relevant books or articles from the University catalogue. Relevant websites were searched, including the FORWARD, FGM network

and FGM National Clinical Group websites. References were hand searched. The search strategy yielded 2,457 relevant pieces of information; 1,535 after duplicates were removed.

The titles or abstracts of sources were scanned for inclusion; information was excluded if FGM was not the main focus or if psychological or emotional consequences were not discussed. This left 71 sources of information to be screened. This process is depicted in *Figure 1*.

Synthesis of the data was approached with a narrative rather than a systematic approach, because of the varied research methods used in the source evidence; however, elements of systematic methodology were used to ensure a comprehensive review.

Figure 1. Flow of information for studies included in the review (Moher, Liberati, Tetzlaff & Altman, 2009)



Screening

The 71 sources were screened for inclusion by reading the full text; 57 sources were excluded (see *Figure 1*). Fourteen studies were included in the final review; 13 were papers and one was a book chapter which reported primary data (four qualitative, three mixed method and seven quantitative sources).

Quality Assessment

Thomas and Harden (2008) provided 12 criteria guidance for quality assessment within a thematic synthesis. For the purpose of consistency in the quality assessment across quantitative and qualitative studies, the Critical Appraisal Skills Programme (CASP) tools were used (Appendix A) (CASP, 2014). Quality assessment for the qualitative research assessed: the study's methodology; recruitment strategies; data collection; consideration of the relationship between the researcher and participants; ethical issues; data analysis; statement of findings and the research value. The quantitative research quality assessment covered: aims and objectives; methodology; recruitment consistency and appropriateness; measurement of exposure and outcomes; discussion and consideration of confounding factors and if there was a clear statement of results, if they were valid and applicable to a local population. Each study was given a rating of high, medium or low quality.

In a traditional systematic review, studies would be excluded or included based on their quality assessment. For the purpose of this review, however, all studies were included, but the quality assessment was considered in the final synthesis.

Context of Research

When conducting a qualitative synthesis, social and political contexts of research and the impact of this on the findings should be considered. FGM has been illegal in the UK since 1985 and is now illegal or restricted in most countries in which it has been performed historically. In 2012 the

United Nations General Assembly recognised FGM as a human rights' violation. In the UK, the government has produced multiagency guidelines for detecting and reporting FGM practises which extends to safeguarding young girls at risk (Department for Education, 2014). FGM is negatively constructed as a practice which is abusive and physically and emotionally damaging to females. When conducting the review, the author was aware of the social context as the frame of reference for both researchers and professionals working with women with FGM. It was important to consider this in the review and how this may impact on the type of research conducted and conclusions drawn. For example, when exploring the impact of FGM, researchers may only ask about the negative impact; therefore, their findings may be biased towards drawing conclusions about only negative consequences of FGM.

Analysis and Synthesis

Data to be synthesised were all of the text (including tables, statistics and direct quotes) labelled as findings or results in the publication (Thomas & Harden, 2008). In managing the diverse methodologies, findings where synthesised in two ways. Quantitative data, which were derived from pre-determined responses from structured questionnaires, were brought together and summarised. The second synthesis focused on the qualitative data, usually from open-ended questions. The methods for Thematic Synthesis were employed (Thomas & Harden, 2008). Data were initially free-coded by hand by the author, from which descriptive themes were developed, similar to the original study's findings. The final stage of synthesis was the development of analytical themes which directly considered the aims of the review. At this stage the descriptive and analytical themes were discussed with another independent researcher. The findings of the quantitative and qualitative syntheses were discussed in relation to the review question.

Results

Quality Assessment

Table 1 contains a summary of the quality assessment for each study.

Quantitative studies.

One quantitative study was rated as high quality (two of the criteria unmet) (Chibber El-Saleh, & El-Harmi, 2011; five of the seven quantitative studies were rated as medium quality (Applebaum et al., 2007; Behrendt & Moritz, 2005; Chalmers & Omer-Hashi, 2000; Elnashar & Abdelhady, 2007; Kizilhan, 2011), as were quantitative aspects of the mixed methods studies. One quantitative study was rated as low quality (Zayed & Ali, 2012).

All but one of the studies had a clear aim and provided a rationale for their methodology; most had acceptable recruitment strategies and provided a clear statement of their results, linking their findings with previous research and knowledge. Only four studies, however, assessed outcome (psychological consequences) in an unbiased way and controlled or accounted for possible confounding variables. Only one study assessed exposure (type of FGM) accurately; most relied on self-reports of FGM. No study reported the findings by type of FGM, thus drawing conclusions about the consequences by type are impossible. Only one mixed method study included migrant populations in the UK, thus no findings from the other studies were directly applicable to local population.

Qualitative studies.

One qualitative study was rated highly, meeting most or all of the assessment criteria (Jones, 2011); one was rated as medium quality, meeting seven of the10 criteria (Hussein, 2010) and the remaining two studies were rated as low quality, because most of the criteria were unmet (Lightfoot-Klein, 1989; Woolard & Edwards, 1997).

Ethical issues were carefully considered and findings were clearly stated in the qualitative studies. The quality assessment, however, also highlighted some issues; thus caution was needed in drawing definitive conclusions from lower quality qualitative studies, included in the review. In only two studies was the relationship between the researcher and participants explored and the impact considered on data collection and analysis; for one study this was the only criterion met. In some studies information was lacking on recruitment strategies; therefore, assessment of bias or replicability was difficult. Many studies were not explicit in their collection methods or analytic process; therefore, it was difficult to assess how the results had been reached. For most of the studies it was unclear as to the overall value of the research.

For the qualitative aspects of the three mixed methods studies, one was rated as high and two medium. For the high quality study there was a lack of detail around data collection and, for the medium, information was lacking about recruitment and data analysis.

Table 1

Quality Assessment

Study	1	2	3	4	5	6	7	8	9	10	11	12	Quality Rating
Hussein, 2010 Q	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	Unclear	n/a	n/a	Medium
Isman et al., 2013 Q	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	n/a	n/a	High
Lightfoot-Klein, 1989 Q	No	No	No	No	No	Yes	No	No	No	No	n/a	n/a	Low
Jones, 2010 Q	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	n/a	n/a	High
Woolard & Edwards, 2010 Q	No	No	No	Unclear	Unclear	No	Yes	No	Yes	No	n/a	n/a	Low
Lockhat, 2004 M	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Unclear	Yes	Yes	Yes	n/a	High Q
	Yes	Yes	Unclear	No	Yes	Unclear	No	Yes	No	Unclear	Yes	Yes	Medium Qt
Vloeberghs et al., 2013 M	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	Yes	n/a	High Q
	Yes	Yes	No	No	Yes	Yes	No	Yes	No	Yes	Unclear	Yes	Medium Qt
Al-Krenawi & Wiesel-Lev (1999) M	Yes	Yes	Yes	Unclear	Yes	No	Yes	Unclear	Yes	Yes	No	n/a	Medium Q
	Yes	Yes	Yes	No	No	Yes	No	Yes	No	Unclear	Unclear	Yes	Medium Qt
Chalmers & Hashi (2000) Qt	Yes	Unclear	Yes	No	No	No	No	Yes	No	Unclear	No	Yes	Medium
Applebaum, et al. (2008) Qt	Yes	Yes	Yes	No	Yes	Yes	No	Yes	No	Yes	No	No	Medium
Behrendt & Moritz (2005 Qt	Yes	Yes	No	No	Yes	Yes	No	Yes	No	Yes	No	Yes	Medium
Chibber, et al. (2010) Qt	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	High
Elnashar & Abdelhady (2007) Qt	Yes	Yes	Yes	No	Yes	No	No	Yes	No	Unclear	No	Yes	Medium
Kizilhan (2010) Qt	Yes	Yes	Yes	No	Unclear	No	No	Yes	No	Yes	No	Yes	Medium
Zayed & Ali (2012) Qt	Yes	Yes	Unclear	No	No	Yes	No	No	No	No	No	Unclear	Low

Legend: Number refers to quality assessment question. Q refers to qualitative studies, M refers to mixed methods and Qt refers to quantitative studies. Q studies 1=Clear statement of results; 2=Appropriate methodology; 3=Appropriate design; 4=Appropriate recruitment; 5= Data collected to address

research issues; 6= Relationship between participants and researcher discussed; 7=Consideration of ethical issues; 8= Rigorous data analysis; 9= Clear statement of findings; 10= Value of research. Qt studies 1=Focussed issue; 2=Appropriate methodology; 3= Acceptable recruitment; 4= Exposure accurately measured; 5=Outcome accurately measured; 6= Consideration of confounding factors; 7= Follow up completed; 8= Statement of results; 9= Precision of results; 10= Results believable; 11=Application to local population; 12=Results fit with other studies.

Description of the Studies

Four studies utilised qualitative methodology; three used semi-structured interviews, one used unstructured interviews and observations and one case study. Three studies employed mixed methods using standardised questionnaires and semi-structured interviews. Seven of the studies used quantitative methodology; six studies compared circumcised females with matched controls of uncircumcised females, one study only examined a circumcised group of women. Standardised and non-standardised questionnaires were used.

The studies were conducted in 10 different countries and half were conducted in the last five years. Most studies included adult females; one was conducted with children under 18 and one with children *and* adults. The participants were from various countries including Bedouin regions of Israel, Djibouti, Egypt, Eritrea, Ethiopia, Kuwait, Senegal, Sierra Leone, Somalia and Sudan. Two studies specified additional inclusion criteria in addition to FGM experiences; one study was conducted with newly married women and one study with pregnant women.

Only four of the 14 studies reported research aims exclusively focused on exploring the psychological or psychiatric consequences for women with FGM; in three studies the aims were linked with psychological consequences and other consequences of FGM (relational, sexual, obstetric or social outcomes) and in seven studies the research aims' foci were more general (prevalence, experience of, or attitude towards FGM).

Result of Quantitative Studies

The findings from the quantitative aspects of the studies related to emotional responses to FGM and rates of psychiatric disorders.

Five quantitative studies reported on general emotional responses to FGM (Behrendt & Moritz, 2005; Chalmers & Omer-Hashi, 2000; Chibber et al., 2001; Kizilhan, 2011; Zayed & Ali,

2012). Three studies reported that information was gathered using a structured questionnaire designed specifically for their studies which, although different for each study, used the same language to report their findings (Behrendt & Moritz, 2005; Chibber et al., 2001; Kizilhan, 2011). The three studies (one high and two medium quality) found that 78-90% of 1,648 participants retrospectively reported feelings of *intense fear, helplessness, horror* and *severe pain* at the time of their circumcision and 74-85% of 1,635 participants reported current *intrusive re-experiencing of their circumcision*.

These figures represent women from Senegal and Kuwait and young girls from Iraq, with all types of FGM, and indicate *very* high rates of negative emotional responses to FGM. The evidence indicates that these women may fulfil at least two of the five areas required for a diagnosis of Post Traumatic Stress Disorder (PTSD) (Criterion A: Stressor and Criterion B: Intrusions) (American Psychiatric Association (APA), 2013). One low quality study, randomly recruited women from Cairo and Giza, also reported that 94.9% of circumcised women (n=148) (61% of overall sample) experienced emotional trauma after FGM. It was, however, unclear how emotional trauma had been established; therefore, caution may be needed in drawing definitive conclusions (Zayed & Ali, 2012). In each of these studies it was unclear if women were asked about positive *and* emotional responses.

In contrast, however, one quantitative study (medium quality), asked about both positive *and* negative emotional responses to FGM in 432 pregnant, migrant Somali women in Canada (Chalmers & Omer-Hashi, 2000). Forty percent reported being afraid before their circumcision,29% reported fear and 28% unhappiness in the days following their procedure. This was much lower than the percentages reported by Behrendt and Moritz (2005), Chibber et al. (2000) and Kizilhan (2011); however, participants were not asked about their feeling during their circumcision. The majority of women in this study also reported positive feelings before their circumcision and the days following; for example, feeling special, happy and proud (79%, 72% and 60%). At the time of the research, the majority also reported current positive feelings about their circumcision; 73% were proud, 53% felt

pure and 30% felt more beautiful; only 16% regretted their circumcision, 5% felt angry and only 3% felt betrayed.

In the Chalmers and Omer-Hashi (2000), over 66% of participants retrospectively reported being excited about their circumcision; 44% were pleased with the plans, indicating preparation for and positive appraisal of the circumcision, which could be pertinent mediating factors for longer term distress. Most participants in Behrendt and Moritz (2005) (78%) reported unexpected and unexplained circumcisions which may have impacted on the way women perceived and appraised their circumcision. The studies reporting on the negative emotional impact, however, did not ask about possible positive feelings (historical or current), which could mean their findings may not reflect the complexity of emotional responses to FGM.

Six of the 10 studies (two of which were mixed methods) reported rates of specific psychiatric disorders; in all but one, the rates were compared to matched control groups (Applebaum et al., 2011; Behrendt & Moritz, 2005; Chibber et al., 2011; Elnashar & Abdelhady, 2007; Kizilhan, 2011; Vloeberghs et al., 2012). Two studies adopted general inclusion criteria (personal experience of FGM) and compared them to control groups matched on marital status, number of children, physical problems, exposure to traumatic events and age (Applebaum et al., 2011; Behrendt &Moritz, 2005). Three studies had additional inclusion criteria: one study was conducted with girls under the age of 18 and compared them to two age matched control groups (from same and different regions) (Kizilhan, 2011), one study compared pregnant women with FGM to a pregnant control group (Chibber et al, 2011) and one study compared newly married women with and without FGM (Elnashar &Abdelhady, 2007). The studies used a range of methods to assess for rates of psychological difficulties and psychiatric disorders, making comparison across studies problematic. The studies were rated as medium or high quality, so the conclusions drawn were unlikely to change, despite criteria being unmet.

Depression or affective disorders.

Six studies reported rates of depression or affective disorders and four reported significantly increased rates. Two studies (Behrendt & Moritz, 2005; Chibber et al., 2011) used the Mini International Neuropsychiatric Interview (MINI); a short structured questionnaire demonstrating good reliability and validity compared to the Composite International Diagnostic Interview and to the Structured Clinical Interview for DSM-IV (Sheehan et al., 1997). Vloeberghs et al. (2012) used the Harvard Symptom Checklist (HTQ-30), which has been validated in cross-cultural and patient studies. Rates of affective disorders ranged from 22-58% in the FGM group, compared to <1-4% in the control groups. Kizilhan (2011) also found that symptoms of depression, using the validated and reliable Children's Depression Index (CDI) (Gharib, 1988), could be used to discriminate between the three groups of young women:FGM (n=79), non-FGM in same region (n=30) and non-FGM from different region (n=31).

Two studies used the Symptom Checklist-90 (SCL-90), used to describe general psychiatric symptoms using 90 items to measure nine clinical subscales (Applebaum et al., 2008; Elnashar & Abdelhady, 2007), which has been found useful in the assessment of neurotic symptoms (Derogatis, 1977). Both studies found no significant difference in rate of depression in women with and without FGM, including those who were newly married. Thus rates of depression are not universally found in women with FGM.

Anxiety related disorders.

The same six studies also reported rates of anxiety-related disorders (general anxiety, somatisation and phobia); four found significant rates of anxiety disorders in women with FGM. Behrendt and Moritz (2005), Chibber et al. (2011) and Vloeberghs et al. (2012) indicated that rates of anxiety disorders were 26-42% compared to none in the control groups, using the MINI. Elnashar and Abdelhady (2007) also found that newly married women with FGM experienced significantly more

rates of somatisation (<0.001), anxiety (<0.001) and phobia (<0.001) compared to controls, using the SCL-90. Using the SCL-90, however, Applebaum et al. (2008) found no significant differences between women with and without FGM; they concluded this was due to their experimental group having more minor forms of FGM, compared with other studies.

Kizilhan (2011) used the Child Diagnostic Interview for Psychiatric Disorders (C-DIPS) (Unnewehr, Schneider, & Margraf, 1995), a structured questionnaire which allows for lifetime and point prevalence of psychiatric disorders based on diagnostic criteria. No significant differences were found on rates of anxiety and somatoform disorders.

Women in studies where significantly higher rates of anxiety were prevalent were from cultures in which FGM was becoming socially or culturally unacceptable or was not practised (migrated culture); two of the studies included women who were going through/had gone through significant life stages (marriage and pregnancy) and one included participants with extreme forms of FGM. This suggests that the views of the wider cultural group, the type of FGM and the stage a woman is on the life cycle may all contribute to anxiety levels. Similar factors may also influence rates of depression.

Post Traumatic Stress Disorder (PTSD).

Five studies explored rate of PTSD, comparing women with and without FGM (Applebaum et al., 2008; Behrendt & Moritz, 2005; Chibber et al., 2011; Kizilhan, 2011; Vloeberghs et al., 2012). As with other psychiatric disorders, a variety of assessment measures were used, meaning direct comparison between studies was problematic. The PTSD Inventory (Solomon et al., 1993), Impact of Events Scale (Zilberg, Weiss, & Horowitz, 1982), Child PTSD reaction scale (Frederick, Pynoos, & Nader, 1992), Traumatic Life Event Questionnaire (Kubany, 1995), the Harvard Trauma Questionnaire (HTQ-30) (Mollica et al., 1992) and the MINI were used. A diagnosis of PTSD requires a *stressor* to which an individual was directly or indirectly exposed, such as death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence (APA, 2013).

Behrendt and Moritz (2005) found significantly higher rates of PTSD in women with FGM (30% of sample) compared to controls (0%), who were assessed for PTSD in relation to other traumatic life events (sudden death of friend/family). Chibber et al. (2011) found similar results and Kizilhan (2011) found significantly higher rates of PTSD symptomology in young girls with FGM, compared with two control groups; however, in the latter two studies it was difficult to establish the stressor on which controls were assessed for PTSD (in the absence of FGM). Vloeberghs et al. (2012) also found that one sixth of their sample experienced PTSD; rates of PTSD were higher in women with Type III, who were older when they were circumcised, remembered the procedure well or had higher levels of education.

Applebaum et al. (2008), however, used two measures of PTSD (PTSD Inventory and IES) and found no significant difference between Bedouin women who were, and were not, circumcised. They concluded their results related to the type of circumcision performed in the sample and the cultural views of the procedure.

Memory.

The Rey Figure Test, designed to assess immediate and delayed visual memory using recall of a complex figure drawing (Lezak, 1995), was used to assess memory problems in two studies. One study found significant differences when comparing circumcised women with PTSD to circumcised women without PTSD and uncircumcised women. Women with PTSD performed significantly worse than the circumcised women without PTSD on both immediate and delayed recall trials (Behrendt & Moritz, 2005). One study found no significant difference on memory, perhaps indicating PTSD contributes to memory difficulties rather than FGM.

Synthesis.

There was a bias in research towards asking about only negative emotional consequences of FGM, possibly indicative of the social context of research. Evidence suggests, however, that if

women are asked about both the positive and negative emotional consequences of FGM, they may report mixed feelings. This indicates the complexity of the emotional response associated with FGM.

The evidence indicates that women who have undergone FGM may be more likely to experience increased rates of anxiety and PTSD and in some circumstances, depression. Most of the studies included recruited low participant numbers, so the findings may be underpowered. Synthesising the findings indicated some possible mediating factors in the development of psychiatric disorders, including the level of preparation, cultural value placed on FGM and the life cycles stage. All these factors may influence how a woman appraises her circumcision and thus her emotional and psychological response. The type of FGM was also proposed as a mediating factor; however, only one study physically examined women on the type of FGM, which makes drawing conclusions based on the type of FGM problematic.

Results of Qualitative Studies

The principles of Thematic Synthesis were used in the analysis of the qualitative data (Thomas &Harden, 2008; Thomas et al., 2003), which included the qualitative data of the mixed method studies. In some studies the psychological and emotional consequences formed a distinct theme; in other studies, they were integrated into other themes. As part of the analytic process, descriptive themes were examined in relation to the review question; only themes which added to the understanding of the psychological and emotional consequences were included in the final synthesis. Themes included emotional responses: FGM is with you for life; mind and body connected; loss; shame and guilt; and protective factors (Table 2). *Figure 2* provides a visual representation of the themes.

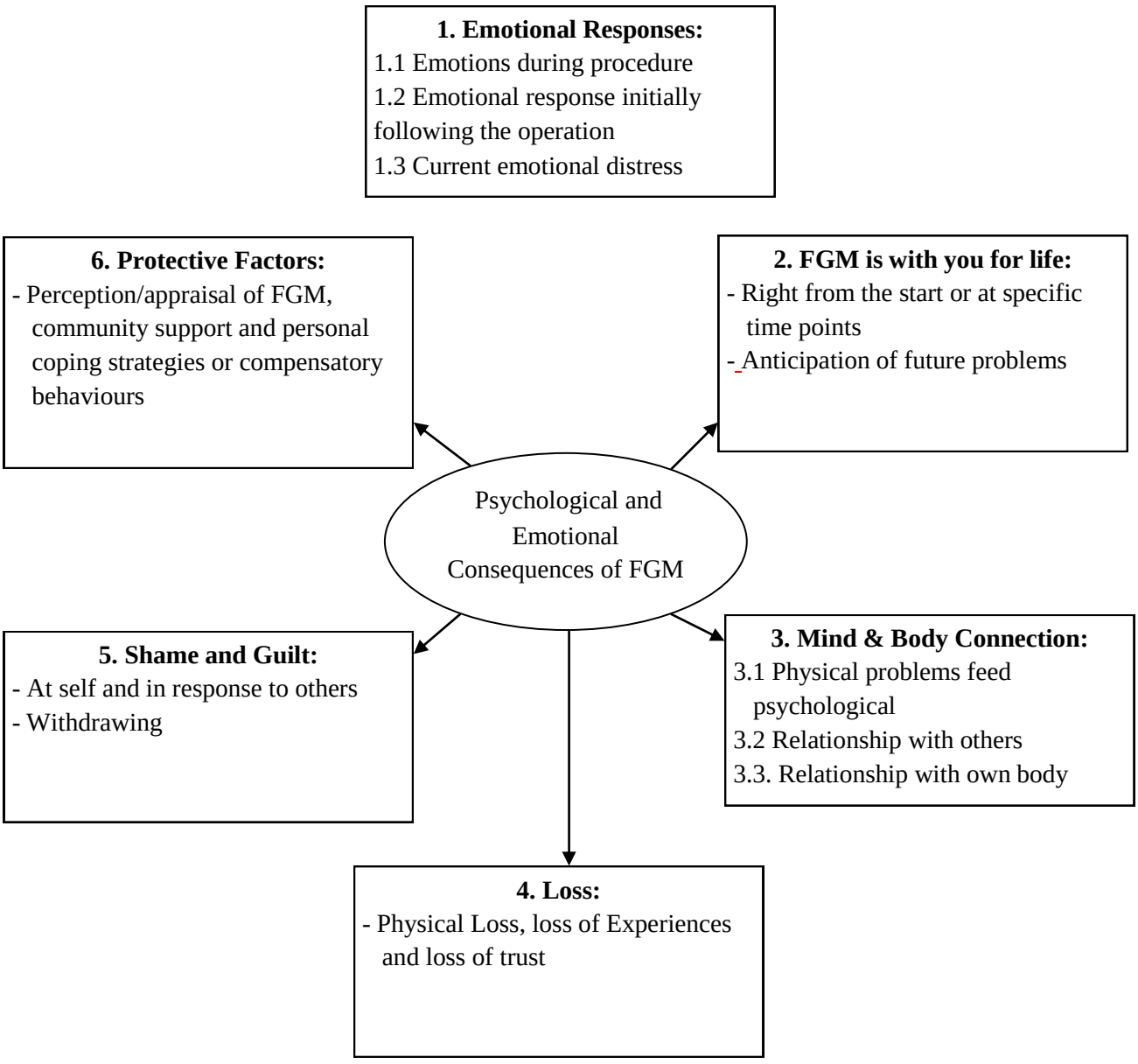
Table 2

Presence of Qualitative Themes

	Emotional responses	FGM is with you for life	Mind and body connected	Loss	Shame and guilt	Protective factors
Hussein, 2010 Q	X	X	X	X	X	
Lightfoot-Klein, 1989 Q	X	X	X	X	X	X
Jones, 2010 Q		X	X	X	X	
Woolard and Edwards, 1997 Q	X			X		
Lockhat, 2004 M	X	X	X	X	X	X
Vloeberghs et al., 2012 M	X			X	X	X
Al-Krenawi and Wiesel-Lev (1999) M	X	X		X		

Note: X shows the presence of the theme in the study.

Figure 2. Synthesis of the themes from the qualitative research.



1. Emotional Responses

General emotional responses to FGM were described in the qualitative literature, including emotions during and shortly after the procedure and current emotional distress. The review was focused on the consequences of FGM; feelings prior to the procedure were not reported.

1.1 Emotions during the operation.

Lockhat (2004) and Al-Krenawi and Wiesel-Lev (1999) reported emotional experiences of women during their operation. Few women were unable to recall their operation; most recalled the experience vividly and there were no references to positive emotions. Women reported feeling helpless, shocked and extreme pain, the response to which was to either scream or suffer in silence.

> "They caught my arms and legs...it is all very stupid, I can remember the pain, I screamed...I screamed for three days..." (Lockhat, 2004, p. 116, Participant 9).

> "I didn't struggle because I was shocked it was happening..." (Lockhat, 2004, p. 116, Participant 30).

> "I felt something was wrong, but did not know what. Another woman was in the room. My mother put me on the bed and then I was circumcised. I screamed and screamed" (Al-Krenawi & Wiesel-Lev, 1999, p. 5).

1.2 Emotional response initially following the operation.

Hussein (2010) reported women felt immediately emotionally and psychologically changed by FGM.

> "I think that the psychological impact starts from the moment of circumcision" (Hussein, 2010, p. 15).

Lockhat (2004) reported that emotional responses in the days following the procedures were varied, and appeared to be mediated by their appraisal of the circumcision and the circumstances surrounding it. Some women reported happiness and pride because it was normal, whilst others experienced sadness and confusion, disbelief, anger and hatred.

> "I felt happy afterwards because I thought everyone has it, it is common..." (Lockhat, 2004, p. 117, Participant 28).

> "I was really sad. I didn't know the implications then..." (Lockhat, 2004, p. 117 Participant 16).

> "We talked about it saying...'I can't believe our mums did this!'...I felt let down...then angry..." (Lockhat, 2004, p. 118, Participant 30).

1.3 Current emotional distress.

All of the studies reported women experienced emotionally distressing feelings following their FGM; these were similar feelings to when they were circumcised, for example pain, tension, fear, distress or feelings of powerlessness and helplessness (Lockhat, 2004; Vloeberghs et al., 2012). For some, emotional reactions were a response to psychological events linked to their FGM experience: e.g. Sadness and depression from intrusive memories of FGM (Lockhat, 2004), bad memories and nightmares (Vloeberghs et al., 2012) and flashbacks (Hussein, 2010). Reports of low mood, intrusive memories and nightmares and physical re-experiencing by women are signs of long term psychological trauma and distress. The qualitative research however is perhaps not limited or constrained by diagnostic frameworks and as such may capture the complexity of the psychological and emotional experiences of women with FGM, which impact negatively on their quality of life.

> "After my first child, I lost a lot of blood and used to have the same shivering feeling I had when I was actually circumcised" (Lockhat, 2004, p. 123, Participant 26).

> "I have to take antidepressants to cope with this..." (Lockhat, 2004, p. 126, Participant 42).

> "I start to tremble all over, and all the memories come flooding back, I cannot do anything for the next few days, and all I want to do is sleep" (Vloeberghs et al, 2012, p. 686).

There were repeated references to women avoiding conversations, events, objects and situations, triggering a re-experiencing of the emotions from the time of the circumcision; however, this was not always supported with direct quotes (Jones, 2010; Lockhat, 2004; Vloeberghs et al., 2012). Avoidance is a key feature in those experiencing PTSD (APA, 2013). Jones (2010) reported that conversations over the negative aspects of FGM are avoided or viewed as taboo.

> "I would avoid sex" (Lockhat, 2004, p. 124, Participant 12).

> "…certain TV programmes..I will not watch something on circumcision..." (Lockhat, 2004, p. 124, Participant 38).

> "…talking about it like now...I don't want to remember...I want to forget...." (Lockhat, 2004, p. 124, Participant 48).

2. FGM is with you for life

Five studies, four of which were rated as high quality, examined the emotional and psychological consequences of FGM at specific points in a woman's life (after marriage, or during and after pregnancy), highlighting the enduring nature of FGM consequences, "FGM is with us every day" (Hussein, 2010, p. 12). The previous theme of emotional responses indicated that some emotional consequences of FGM emerge immediately following the procedure and may remain with a woman throughout her life.

> "For some reason I became a frightened woman because of what they told me during my genital mutilation. They said 'you will be visited by a deceased person during your sleep'. They made it seem so real. I believed it. Since then I'm just scared all the time, and I cannot

> be home alone...this is all due to my circumcision. If a man makes a scary joke, it can get to me that hard it just ruins my whole day. Then I get really pissed off. Therefore, I say to my boyfriend that he may never surprise me or touch me from behind, nor should he address me secretly. And he does not dare make scary jokes with me" (Vloeberghs et al., 2012, p. 684).

For some, negative emotional and psychological consequences emerged at "various stages throughout their life" (Jones, 2010, p. 25). Pertinent periods for psychological fragility surrounded times when a women experienced physical and emotional changes (e.g, puberty and menstruation, marriage, pregnancy and childbirth).

> "The big night or the wedding night is supposed to be the happiest night in the woman's life. But for a woman who has FGM it becomes the worst night of her life." (Hussein, 2010, p. 15).

> "I heard about a lady who had depression and after she had her delivery because of the complications..." (Jones, 2010, p. 55, Participant 1).

> "Almost all have problems...the main ones are at the time of marriage and childbirth...but how and when you will have problems is not predictable. Problems can appear at any stage in the lifecycle..." (Lockhat, 2004, p. 131, Participant 38).

Women in the Jones (2010) study highlighted the need for the professionals working with women with FGM to acknowledge the experience remains with a woman for life. perhaps making links with current emotional distress (1.3) and their early experience of FGM.

> "Maybe they don't know that FGM is a part of the problems but it's better if I think if when a person is depressed or something like that you go to the roots and find out that they might have had FGM..and er this is the important part: maybe she doesn't know about it but when they put you on a bed with all the women around you and everyone and you screaming and maybe they don't know and think this is all in their mind but if they talk about it they

> might realise that FGM is a part of that depression...the psychologist should know all these parts" (Jones, 2010, p. 57-58, Participant 3).

Women may also experience emotional distress in relation to anticipating future emotional or physical problems. The anticipation of problems from theme two was linked with theme three (mind and body connection), perhaps because of the emotional burden of anticipating and managing future physical difficulties.

> "Young girls may suffer from depression, knowing that they will have even bigger problems about FGM in the future after they marry" (Hussein, 2010, p. 14).

> "How and when you have problems is not predictable...problems can appear at any stage in the life cycle...those who don't have problems early on may suffer later on. But you never escape that feeling of anxiety, not knowing if you will have problems or not. That fear can change you" (Lockhat, 2004, p. 122, Participant 38).

3. Mind and Body Connection

Throughout the qualitative studies, most of which were high-medium quality, there was a strong link between physical changes and the impact on women's emotional experiences, their relationship with others and their own body (Hussein, 2010; Jones, 2010; Lightfoot-Klein, 1989; Lockhat, 2004; Vloeberghs et al., 2012).

3.1. Physical problems feed psychological.

Emotional responses (theme one) were linked with experiencing physical complications from their FGM. Jones (2010) explained how the physical complications during and following labour can affect women emotionally and Vloeberghs et al. (2012) described how physical pain and problems cause impediments on mental and social levels.

> "They have problems and you know there are lots of complications..erm...so this could be one of the reasons the physical problems and they feed the psychological problems" (Jones, 2010, p. 52, Participant 5).

This may provide an explanation for the variation in the emotional and psychological consequences to FGM. Lockhat (2004) suggested women who experience post-circumcision physical complications may be more likely to go on to experience psychological difficulties including PTSD. Hussein (2010) described how the pain of FGM impacts of the physical, psychological and sexual aspects of a woman's life; the pain endured during the first cutting experience was repeated during sexual intercourse; psychologically this is like reliving the first experience of pain, again.

> "The pain you endure during the cutting and then when you have sex for the first time, every time someone touches your private parts, you think 'here comes the pain again'" (Hussein, 2010, p. 13).

3.2. Relationship with others.

Sexual problems, usually as a result of pain during penetration, can impact on a woman's relationship, affecting their confidence and self-esteem, sometimes leaving them feeling responsible for their husband's infidelity (Al-Krenawi & Wiesel-Lev, 1999; Jones, 2010; Lockhat, 2004).

> "I will have a problem when I marry. The groom will run away from me. I may think of suicide at my wedding day...Men are not to blame for it, but I will not be able to have sex with them. I think my husband will treat me well but I will be the problem" (Al-Krenawi & Wiesel-Lev, 1999, p. 6).

> "One friend has never been married and the other sister is 30 and her husband has cheated in her...she's got 2 sons at home and he's cheated on her and everything with her comes back to that [FGM] and she thinks that if that was ok then none of this would have happened and so

the blame...to think about how it's made them feel and how it's made them sort of see themselves" (Jones, 2010, p. 55, Participant 2).

3.3. Relationship with own body.

Depression and anxiety may also be driven by a body consciousness. Some woman reported an awareness of the appearance of their genitals in comparison to other women, who were uncircumcised (Lockhat, 2004), which left them feeling "ugly down there" (Hussein, 2010, p. 14).

"Mainly disfigurement..I was conscious about it as a teenager very much...although everyone had it done. I still felt disfigured...I guess in the same way that someone who had a big nose or something would feel self-conscious" (Lockhat, 2010, p. 126, Participant, 15).

"The scar is something that I have become conscious about since I have been in the UK" (Lockhat, 2010, p. 126, Participant, 21).

"I felt I was an abnormal shape" (Lockhat, 2010, p. 126, Participant, 16).

4. Loss.

All of the studies provided supporting evidence for the theme of Loss, which describes the physical loss of a body part, the loss of experiences and the loss of trust following FGM. "Loss associated with something physically being removed was described by some participants as was loss in relation to missing out on particular experiences" Jones (2010, p. 56).

Throughout the qualitative literature, references to the irreversible and permanency of changes, were made. Some woman may experience grief at the impossibility of undoing FGM; in some cases, physical loss was experienced as a theft.

"After time she may feel that they have taken or stolen from her something private that belonged to her" (Hussein, 2010, p. 14).

> "I felt that they were two heartless animals who had stolen a piece of my body" (Al-Krenawi & Weisel-Lev, 1999, p. 5).

Loss was also related to women missing out on experiences due to their FGM. Women described losing their dignity and missing out on sexual experiences such as desire, pleasure and orgasm, and also parenting due to the fear of the physical complications of FGM during childbirth (Hussein, 2010; Jones, 2010; Lightfoot-Klein, 1989).

> "Some of them say we do not want to marry we do not want to have children, you know...er it's traumatic in some cases" (Jones, 2010, p. 58, Participant 6)

> "I discovered that FGM deprived me of most of my sensation. Even if I do feel it is not that much. I sometimes feel that my husband is trying his very best to help me have a sexual sensation and it takes me a long time to have any feeling" (Hussein, 2010, p. 15).

For some, the physical loss at the hands of another person was viewed as a transgression of the trust in others. Women expressed the loss of trust in their hatred towards other people, including their parents, their husbands or the person who performed the procedure; for some, this had a life-long impact on their ability to trust others. Women may be wary of niceties because this method may have been used by to entrap them.

> "The cruelty starts with suspicion from the girl who is in love with her family, she cannot be able to believe that her heart that her mother could be involved in that [FGM] so the girl will feel lonely" (Hussein, 2010, p. 14).

> "When I remember the man who did it...I feel I'd like to kill him...he was educated...a doctor..he should have known better" (Lockhat, 2004, p. 125, Participant 17).

> "I started to hate all people. They are all thieves...they lie, give candies to do something wrong" (Al-Krenawi & Weisel-Lev, 1999, p. 5-6).

5. Shame and guilt.

Many women talked about experiencing shame and guilt, for many reasons. Some women talked about guilt and shame at their reactions during and after their procedure, whilst other women experienced guilt and shame in response to other people, sometimes resulting in social withdrawal.

Hussein (2010), Jones (2010) and Vloeberghs et al. (2012) all make references to the shame at the outward expression of pain during the procedure. Women from cultures who practice FGM are often raised to believe pain should be endured in silence, to oneself; a violation of this belief brings shame to the individual. Shame and guilt were also experienced by some women in response to the reactions of other people. Some women felt guilt for expressing pain or complaining of physical problems because there were other women who were worse off (Lockhat, 2004). There was also a sense of guilt of being unable to protect others from FGM.

> "You always think your problems may not be much compared to what others may have" (Lockhat, 2004, p. 125, Participant, 35).

> "Very angry...I don't want to see that pain on anyone's face" (Lockhat, 2004, p. 125, Participant 18).

For some women who remained within the cultural group which practiced FGM, circumcision was a way of avoiding shame from feeling different to other women and being mocked. In some circumstances, the risk of shame from being uncircumcised meant that individuals lied about their FGM status.

> "There (Sudan), women laugh and tease uncircumcised women...so you feel normal with it" (Lockhat, 2004, p. 133, Participant 14).

> "My sister is now 15 and my mum didn't do that for her...but you know none of my relatives know that...if they know that she didn't do that for my sister they wouldn't accept…she said

> that she did it for her when she was in another town but didn't...but the community would not accept that" (Jones, 2010, p. 47, Participant 6).

For those, however, who had migrated into a new non-FGM practicing cultural group, shame was experienced *because* of their FGM. These women reported feeling different compared to women who had not been circumcised.

> "When I go to health centre I feel I am different from other women" (Hussein, 2010, p. 12).

> "No we are ashamed to talk about this thing" (Hussein, 2010, p. 11).

In some cases, shame stemmed from the appearance of their genitals and this led women to delay seeking help (Vloeberghs et al, 2012), sometimes because of the response of professionals. Like with beliefs around expression of pain, beliefs also emerged about seeking help and talking about FGM.

> "I think you suffer in silence because you are meant to be happy, just accept it and not complain" (Lockhat, 2004, p. 132, Participant 44).

> "All the women usually try to avoid being examined in that they don't feel comfortable" (Hussein, 2010, p. 11).

> "You can see the facial expressions of the nurse, the doctor, the midwife. You can see their faces, the range of emotions and how they feel looking at my body. That hurts...those people's eyes make you feel sick" (Vloeberghs et al., 2012, p. 687).

Women often delayed seeking help, particularly with psychological difficulties until problems were very severe, because of the additional stigma (Jones, 2010).

> "They go to the doctor but I think you know in my country it's a shame to go to a psychiatric doctor" (Jones, 2010, p. 64, Participant 1).

The evidence suggests that shame experienced by women, both those who have migrated or not, stems from a comparison of their self (and their FGM status) with the model for the cultural group of what is *normal*. So, for women who live in a cultural group with strong pro-FGM beliefs, to be uncircumcised brings shame; however, for circumcised women in a cultural group that is anti-FGM (whether in their home country or migrated country), shame may be experienced, leading to social withdrawal and feelings of loneliness and isolation (Hussein, 2010; Vloeberghs et al., 2012).

> "You cannot share that with other people. You feel terribly embarrassed. That is why circumcised women become isolated, mentally ill or mad. Either that or she stops talking, she keeps her mouth firmly shut. And nobody understands why...and because we feel ashamed, we stay home with our problems" (Vloeberghs, 2012, p. 685).

6. Protective factors.

It was evident, however, that not all women experienced adverse psychological and emotional responses to FGM; women remaining with their native cultural group, in particular, expressed pride and satisfaction at being circumcised. The previous themes (mind and body connected, loss, shame and guilt) were linked with the theme of protective factors. Women within a pro-FGM cultural group experienced both less shame and negative emotional difficulties. Women whose perception of FGM as being done *for* them, rather than something done *to* them, would perhaps be less likely to see the procedure as a theft, betrayal or a breach of trust. Women who experienced fewer physical complications following their FGM may also experience fewer emotional difficulties, as discussed in the theme mind and body connected.

Lockhat (2004) suggested that community support may also serve as a protective factor against psychological adversity, which may also contribute to the psychological difficulties experienced in migrant women.

> "When in the community if you have problems you can accept them, but if you are outside of the community you don't have the support so you think more and have no emotional support" (Lockhat, 2004, p. 134, Participant 45).

Lockhat (2004) found that for some, celebrations surrounding their procedure and the gifts they received compensated for what they had endured, leading to the appraisal of FGM as a positive experience and thus protecting against long term adversity.

Individual factors, such as effective coping strategies (looking forward, not backwards, using exercise or religion) (Vloeberghs et al. 2012), and the development of compensatory behaviours may also protect against the development of difficulties. For example, Lightfoot-Klein (1989) explained that if women experienced a loss of sensation in their genitals, but were able to experience sexual pleasure in other ways (in their breasts), this may protect against depression.

Discussion

The review aimed to synthesis the qualitative and quantitative evidence for the psychological and emotional consequences of FGM. The quantitative studies used the framework of psychiatric disorders to discuss possible consequences of FGM and as such may have been constrained by the use of these frameworks. They found that some may experience more anxiety, PTSD and depression; however, increased rates were not universally found. The themes from the qualitative sources outlined the complex psychological process beyond diagnostic thresholds, including shame, guilt and loss, which women endure throughout their life. Evidence indicated that not all women with FGM experience psychological difficulties, and thus the review served to outline some of the protecting factors mediating psychological adversity.

Both the qualitative and quantitative studies described similar emotional reactions of women during and after their FGM procedures. The diverse, initial emotional responses to FGM were highlighted. Some women experienced terror, fear, anxiety and extreme pain during and after their FGM experience, whilst others reported that women may also feel special and proud of their circumcision. Positive emotional experiences were reported less; however, it was evident that researchers may be biased towards asking about only negative emotional experiences.

The quantitative evidence examined the longer-term psychological consequences of FGM, in terms of prevalence of psychiatric disorders in women with and without FGM. Some studies found rates of affective and anxiety disorders and PTSD to be significantly higher in those with FGM (Behrendt & Moritz, 2005; Chibber et al., 2011; Elnashar & Abdelhady, 2007; Kizilhan, 2011). The qualitative studies however provided evidence of the complex psychological processes and consequences of FGM, including initial *emotional responses, loss, shame and guilt.* The qualitative themes also described avoidance of events, objects and places relating to FGM procedures, as this triggers intrusive re-experiencing or nightmares of their FGM. These qualitative descriptions may

provide evidence for ongoing psychological trauma and re-living of FGM experiences, for which women may need professional support.

Loss, shame and guilt were significant themes in the qualitative synthesis. Loss has been postulated as a key theme for individuals experiencing depression (Beck, 1967; Moore & Garland, 2004) and Gilbert (2009) suggests poor self-compassion and shame inducing, self-critical, hostile ruminative-thinking styles are characteristic of those experiencing symptoms of depression. The theme of loss also highlighted that women may view their FGM as a breach of trust. It has been suggested that exposure to this type of massive trauma causes a *rupture* and *fixity* of the psyche leaving the individual vulnerable to subsequent complex trauma (Danieli,1998), resulting in a mind-body-brain (neuronal) experience that alters a child's biology, sense of self, consciousness, and relational attachments (Raya, 2010).

The review highlighted the way women appraise their FGM procedure influenced their emotional responses and longer-term psychological well-being. Women, who were prepared, understood and accepted the reasons why their FGM was performed and who remained in a pro-FGM cultural group, were generally less likely to experience adversity. These women were perhaps more likely to perceive FGM as serving a positive function for their future and may have been less likely to perceive FGM as a breach of their trust in significant others. Remaining uncircumcised would bring shame, bullying, peer pressure and isolation from others. In these circumstances FGM may serve to protect against psychological adversity. This may be pertinent for migrant women or those within a cultural group with changing view on FGM. These women may be particular vulnerable to feelings of shame, and may lack emotional support from their wider community. They may also feel different to other women and so isolate themselves to avoid further shame. For future research, it will be important to consider the wider social context in which women are living and the impact this may have on their psychological well-being.

Psychological vulnerability may also be linked with the stage a women in on the life cycle. Chibber et al. (2011) and Elnashar and Abdelhady (2007) provided some limited support for the themes 'FGM is with you for life and 'mind and body connected'. They explored the rates of psychiatric disorders in newly married and pregnant women with FGM. FGM may serve to prevent pre-marital sex; therefore newly married women may be facing their first sexual relationship. The qualitative synthesis indicated that sexual intercourse can be associated with pain and discomfort, which may remind women of their FGM, triggering emotions experienced at the time; e.g., anxiety, fear and panic. Elnashar and Abdelhady (2007) found significantly higher rates of anxiety in newly married women with FGM. Chibber et al (2011) found pregnant women in Kuwait with FGM experienced more anxiety and PTSD than uncircumcised women. It is possible these women will experience physical changes within their body, and may have been exposed to information about the possible physical complications in childbirth, which may trigger worry and anxiety about the future. Future research may potentially explore the experience of pregnancy to understand further women's anxiety and the support they may need during pregnancy.

Limitations

Lockhat (2004) was the only book chapter in the review, because it included primary research data and was repeatedly referenced in the works of others. This highlights a potential limitation; an internet search for books which included the review search terms revealed over 4,000 results, therefore some evidence may not have been included. The review was limited to include research which was presented in English. Given that the practice of FGM is usually within non-English speaking countries, it is possible that further evidence may have been missed.

Implications of the review

The review indicated that women with FGM may be vulnerable to shame, in particular within the context of being with others, including care professionals. The perception of responses of care professionals may impact on the perception of current care and future help seeking behaviours. This

may particularly pertinent during significant life events when women may need extra care, for example, during pregnancy or during/after puberty.

The review also highlighted the diverse and complex psychological and emotional responses to FGM. Considering this, it appears important research is framed in an exploratory, non-judgemental way, without making assumptions about consequences being positive or negative. In doing so, researchers can acknowledge the complexity of responses to FGM, and frame research in a way that does not shame or isolate women.

Conclusion

It was evident that not all women experience adverse psychological difficulties from FGM; for some women, however, FGM was associated with feelings of shame, loss and emotional distress which included anxiety, depression and PTSD. Those who shared positive beliefs about FGM with their cultural group, and those who had effective personal coping strategies experienced fewer difficulties.

Puberty, marriage and pregnancy may be particularly vulnerable periods for women psychologically, because of the physical changes and complications. More research is needed to explore and understand women's experiences during these pertinent life stages and their experiences with healthcare professionals.

References

Al-Krenawi, A., & Wiesel-Lev, R. (1999). Attitudes toward and perceived psychosocial impact of female circumcision as practiced among the Bedouin-Arabs of the Negrev. *Family Practice, 38,* 431-443.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders.* Washington, USA: American Psychiatric Association.

Applebaum, J., Cohen, H., Matar, M., Abu Rabia, Y., & Kaplan, Z. (2008). Symptoms of posttraumatic stress disorder after ritual female genital surgery among Bedouin in Israel: Myth or reality? *Primary Care Companion to the Journal of Clinical Psychiatry, 10*(6), 453-456.

Beck, A.T. (1967). *Depression: Clinical, experimental, and theoretical aspects.* New York: Hoeber. Republished as *Depression: Causes and treatment.* Philadelphia: University of Pennsylvania Press.

Behrendt, A., & Moritz, S. (2005). Posttraumatic stress disorder and memory problems after female genital mutilation. *American Journal of Psychiatry, 162,* 1000-1002.

Berg, R.C., Denison, E., & Fretheim, A. (2010). *Psychological, social and sexual consequences of female genital mutilation/cutting (FGM/C): A systematic review of quantitative studies.* Oslo, Norway: Norwegian knowledge centre for the health sciences. nr 13 - 2010. ISBN 978-82-8121-350-0.

Chalmers, B., & Omer-Hashi, K.O. (2000). 432 Somali women's birth experiences in Canada after early female genital mutilation. *BIRTH, 27*(4), 227-234.

Chibber, R., El-Saleh, E., & El Harmi, J. (2011). Female circumcision: Obstetrical and psychological sequelae continues unabated in the 21st century. *The Journal of Maternal-Fetal & Neonatal Medicine: The Official Journal of the European Association of Perinatal Medicine, the*

Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians, 24(6), 833-836. doi:10.3109/14767058.2010.531318

Critical Appraisal Skills Programme (CASP) (2014). Cohort study checklist_14.10.10. Oxford: CASP.

Critical Appraisal Skills Programme (CASP) (2014). Qualitative research checklist_14.10.10. Oxford: CASP.

Derogatis, L.R. (1977). *The SCL-90 manual F: Scoring, administration, and procedures of the SCL-90*. Baltimore, USA: John Hopkins University.

Elnashar, A., & Abdelhady, R. (2007). The impact of female genital cutting on health of newly married women. *International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics, 97*(3), 238-244.

Frederick, C., Pynoos, R., & Nader, K. (1992). *Child post traumatic stress disorder index*. California, USA: Pynoos Adult Psychiatry.

Gharib, A.G. (1988). *Child's depression inventory.* Cairo, Egypt: Al-Nahda Publishers.

Gilbert, P. (2009). *The compassionate mind.* London, UK: Constable & Robinson Ltd.

Department for Education, Home Office. (2014). *Multi-agency practice guidelines: Female genital mutilation*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/380125/MultiAgencyPracticeGuidelinesNov14.pdf

Hussein, E. (2010). *Women's experiences, perceptions and attitudes of female genital mutilation*. London, England: Foundation for Women's Health, Research and Development (FORWARD).

Jones, A. (2010). *Working psychologically with female genital mutilation: An exploration of the views of circumcised women in relation to better psychological practice* (Doctoral dissertation). Retrieved from British Library EThOS. (ethos.015941094.)

Kizilhan, J.I. (2011). Impact of psychological disorders after female genital mutilation among Kurdish girls in Northern Iraq. *European Journal of Psychiatry, 25*(2), 92-100.

Kubany, E.S. (1995). Unpublished work in Behrendt, A., & Moritz, S. (2005). Posttraumatic stress disorder and memory problems after female genital mutilation. *American Journal of Psychiatry, 162*, 1000-1002.

Lezak, M.D. (1995). *Neuropsychological assessment (volume 3).* Oxford, UK: Oxford University Press.

Lightfoot-Klein, H. (1989). Rites of purification and their effects: some psychological aspects of female genital mutilation. *Journal of Psychology & Human Sexuality, 2*(2), 79-91.

Lockhat, H. (2004). *Female genital mutilaton. Treating the tears.* England: Middlesex University Press.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (The PRISMA Group). (2009). *Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement*. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

Mollica, R., Caspin-Yavin, Y., Bollini, P., Truong, T., Tor, S., & Lavelle, J. (1992). The Harvard trauma questionnaire. Validating a cross-cultural instrument for measuring torture, trauma and post traumatic stress disorder in Indochinese refugees. *The Journal of Nervous and Mental Disease, 180*, 110-115. doi:10.1097/00005053-199202000-000008.

Moore, R.G. & Garland, A. (2004). *Cognitive therapy for chronic and persistent depression.* Chichester, England: John Wiley & Sons Ltd.

Sheehan, D.V., Lecrubier, Y., Sheehan, K.H., Amorim, P., Janvas, J., Wellier, E., Hergueta, T., Baker, R., & Dunbar, G.C. (1997). The validity of the Mini International Neuropsychiatric Interview (MINI): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. *Journal of Clinical Psychiatry, 59*(20), 22-33.

Solomon, Z., Benbenishty, R., Neria, Y, et al. (1993). Assessment of PTSD: Validation of the revised PTSD inventory. *The Israel Journal of Psychiatry and Related Sciences*, *30*, 110-115.

Thomas, J., & Harden, A. (2008). Methods for the systematic review of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*, 45-55.

Thomas, J., Sutcliffe, K. Harden, A., Oakley, A., Oliver, S., Rees, R., Brunton, G., & Kavanagh, J. (2003). *Children and healthy eating: A systematic review of barriers and facilitators.* London: University of London, EPPI-Centre.

Unnewehr, S., Schneider, S., &Margraf, J. (1995). *Diagnostisches interview bei psychischen storungen bei kindern und jugendlichen (Kinder-DIPS).* Berlin, Germany: Springer.

Vloeberghs, E., van der Kwaak, A., Knipscheer, J., & van der Muijsenbergh, M. (2012). Coping and chronic psychosocial consequences of female genital mutilation in the Netherlands. *Ethnicity & Health, 17*(6), 677-695.

Woolard, D., & Edwards, R.M. (1997). Female circumcision: An emerging concern in college healthcare. *Journal of American College Health, 45*(5), 230-232.

World Health Organisation (2000). *A systematic review of the health complications of female genital mutilation including sequelae in Childbirth.* Geneva, Switzerland: World Health Organisation. Retrieved from http://www.who.int/gender/other_health/en/systreviewFGM.pdf

World Health Organization. (2008) *Female Genital Mutilation. Fact Sheet Number 241.* www.who.int/mediacentre/factsheets/fs241/en/ (Last accessed: December 27 2014).

Zayed, A.A., & Ali, A.A. (2012). Abusing female children by circumcision is continued in Egypt. *Journal of Forensic and Legal Medicine, 19*, 196-200.

Zilberg, N.J., Weiss, D.S., & Horowitz, M.J. (1982). Impact of events scale: a cross-validation study and some empirical evidence supporting conceptual model of stress response syndromes. *Journal of Consulting and Clinical Psychology, 50*, 407-414.

Chapter Two

Empirical Paper

An exploration of the psychological and emotional needs of pregnant women who have undergone female genital mutilation (FGM)

Victoria R. Higham

University of Liverpool

Professor Pauline Slade

University of Liverpool

Dr Joanne Topping

Liverpool Women's NHS Foundation Trust

Author Note

Victoria R. Higham, Department of Clinical Psychology, University of Liverpool; Professor Pauline Slade, Department of Clinical Psychology, University of Liverpool; Dr Joanne Topping, Department of Obstetrics, Liverpool Women's NHS Foundation Trust. [2]

[2] To be submitted to the Journal of Health Psychology: An Interdisciplinary, International Journal.

Abstract

Background: Female Genital Mutilation (FGM) may put women at additional physical risks during pregnancy, which may leave them psychologically vulnerable. Pregnancy and childbirth research with women with FGM has focused on the physical risks and the outcomes of pregnancy for mother and child (Paliwal, Ali, Bradshaw, Hughes & Jolly, 2013; Small et al., 2008; Zenner, Liao, Richens & Creighton, 2013; WHO, 2006). The psychological needs of pregnant women with FGM are under researched in the UK, or have relied on retrospective accounts given many years after pregnancy. Aims: To explore the psychological and emotional needs of pregnant women with FGM and their experience of FGM, pregnancy and pregnancy-related care. Methods: Seven pregnant women were interviewed using semi-structured interviews, which were recorded and transcribed verbatim. Transcripts were analysed using Thematic Analysis (Braun & Clarke, 2006). Results: Five main themes emerged, which related to how women made sense of their FGM procedure (*The shame of FGM*) and how this impacted on their experience of pregnancy (*Suffering*), as well as their experience of care during their pregnancy (*women with FGM need to feel cared for*, *information sharing*, and s*pecialised/individual care*). The study highlighted the profound suffering of pregnant women with FGM, in particular their fear of labour and birth. The study was limited as recruitment was from specialist FGM services; however, in doing so the need for specialist services, with professionals who are knowledgeable and experienced with FGM-related pregnancy care, was emphasised. Conclusions: The study added to the understanding of how pregnant women with FGM experience their pregnancy and their maternity care, identifying the crucial aspects of specialist FGM.

Keywords: Female genital mutilation, female genital cutting, female circumcision, psychological, emotional, anxiety, depression, mental health, pregnancy, needs, maternity services.

Introduction

Female Genital Mutilation (FGM) is used to describe procedures involving injury to, or partial or total removal of the external female genitalia for non-medical reasons. The World Health Organisation (WHO) (2008) developed a classification system, to identify the types of FGM: Type I, partial or total removal of the clitoris and/or the prepuce (clitoridectomy), also known as *Sunna* in some cultures; Type II, partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision); Type III, narrowing of the vaginal orifice with creation of a covering seal using the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation); and Type IV, other harmful procedures (pricking, piercing, incising, scraping and cauterisation).

Women with Type III may undergo reversals (de-infibulation), often before their wedding night or childbirth. The reversal involves cutting through the covering seal and stitching the skin on either side of the scar to keep it from healing together; in some circumstances women may be *opened* by their husband's penis on their wedding night. Some women may experience a cycle of infibulation, de-infibulation and re-infibulation (re-closing), with each child.

Within the United Kingdom (UK), an estimated 66,000 women live with FGM. The physical consequences may include bleeding, pain, scarring, reproductive, urinary and genital infections, childbirth complications and death (WHO, 2000). Additionally women may also experience psychological complications, including increased rates of psychiatric disorders and a sense of loss, shame and guilt, impacting on their relationships, body image and confidence throughout their life (see Chapter One, Literature Review).

FGM was made illegal within the UK in 1985 through the Prohibition of Female Circumcision Act (1985) and was extended in 2003 to cover UK nationals circumcised abroad (FGM Act, 2003). Despite the legislation, an estimated 23,000 females under eight years of age may remain at risk of FGM in the UK (Dorkenoo, Morison & MacFarlane, 2007). In February 2014 it was

announced that the first two prosecutions under the FGM Act (2003) would take place. The first prosecution was of a medical professional who allegedly performed a re-infibulation; a second medical professional was charged with aiding, abetting or counselling his colleague.

Pregnancy is a crucial life transition with psychological, relational and emotional risks (Nicolson, 2010), requiring major physical and psychological adaptations. Pregnancy can bring many emotional changes for the mother, her partner and members of the family; for some the upheaval can result in mental health problems (Department of Health (DoH), 2009). Good-quality research is needed to facilitate women to maximise their psychological well-being during pregnancy (Slade & Cree, 2010). Pregnancy may also be the time for interventions promoting attachment and positive parenting, and to reduce longer term mental health problems, which can have serious consequences for the health and well-being of the mother, her baby and their family (DoH, 2009; National Institute for Health and Clinical Excellence (NICE) (2007).

Pregnant women with FGM may represent a vulnerable group, requiring additional support from maternity and ante-natal services. The physical consequences associated with FGM can present complications in pregnancy and childbirth including the need for de-infibulation or reversal (opening of the vagina after Type III) in pregnancy, difficulties in monitoring labour, bleeding and tears, leaving some women psychologically vulnerable. Research into pregnancy and birth experiences of women with FGM has focused on the physical outcomes of labour, including tears, use of surgical interventions (episiotomy, forceps, caesarean section (c-section)), blood loss and haemorrhaging and the outcomes of the baby (premature birth, Apgar scores[3] and stillbirths) (Paliwal, Ali, Bradshaw, Hughes & Jolly, 2013; Small et al., 2008; Zenner, Liao, Richens & Creighton, 2013; WHO, 2006).

[3] The Apgar scale (Apgar, 1953) is simple method to quickly assess the health of newborn children immediately after birth on five criteria (Appearance, Pulse, Grimace, Activity and Respiration).The criteria are scored from zero to two; then scores are added up and totalled to give their Apgar score from zero-10.

National guidance recommends those involved in caring for women during the perinatal period are familiar with the normal emotional and psychological changes which take place during pregnancy and post-natally (Department for Education and Skills, 2004). The needs of women with FGM in pregnancy may be complex and require additional medical, obstetric *and* psychological support to maximise their well-being. High quality research and guidance on how to support the complex needs of women with FGM is needed.

Research into the psychological needs of pregnant women with FGM is limited, relies on third person accounts, or is conducted outside of the UK where maternity services and training may differ from the UK. Research conducted with women with FGM from Spain indicated anxiety triggered by physical examinations in pregnancy (Pereda & Perez-Gonzalez, 2012) and research conducted with midwives in Sweden echoed the findings; midwives expressed concerns about re-traumatising women with FGM during physical examinations (Widmark, Leval, Tishelman & Ahlberg, 2010).

Research from Sweden, Norway and the USA also showed that women with FGM may experience fear and anxiety in pregnancy in relation to labour; poor knowledge or suboptimal care from professionals may exacerbate the fear and anxiety (Lundberg & Gerezgiher, 2008; Vangen et al., 2004). D'Entremont, Smythe and McAra-Couper (2013) also found that fear and shame in pregnancy may come from the culture of silence about FGM amongst care professionals; poor communication about FGM can lead women to lack confidence in professionals and feel unsafe in labour. Research conducted with care professionals in the UK has indicated that continuity of care is important for women with FGM and mismanagement of care may lead to birthing complications (Straus, McEwen & Hussein, 2007).

Fear was also reported in relation to C-sections (Amereskere et al., 2011; Brown, Carroll, Fogarty & Holt, 2010; Lundberg & Gerezgiher, 2008; Murray, Windsor Parker & Tewfik, 2010), because of the possibility of death or disability. All of the studies have, however, relied on retrospective accounts, where women look back over their pregnancy experience. Their accounts and

ideas for support needed during pregnancy may have been influenced by their birthing or postnatal experiences. Some women gave their accounts of pregnancy and labour in excess of five years after the experiences; thus the reliability or accuracy may be questioned.

To the best of the author's knowledge, there are no studies examining the experience of pregnancy with women with FGM and their psychological and emotional needs at this time in the UK. The study attempted to address the gap in the literature.

Aim and research questions

The aim of the study was to explore the experience of pregnancy and the psychological and emotional needs of women with FGM accessing maternity services.

The study was particularly interested in:

- What is it like to be pregnant and a women with a female circumcision receiving care from maternity services in the UK? How is this linked with the personal experiences of FGM?
- How circumcised women experience the physical investigations associated with being pregnant?
- How pregnant women with FGM experience the health professionals providing their care; for example, midwives, doctors and perinatal mental health workers (including clinical psychology), during their pregnancy?

Method

Participants

Potential participants had to be over 18 years of age, pregnant during participation and have personal experience of any type of FGM; women were also included if they had undergone or had plans to undergo a reversal. The reversal opens the narrowed entrance to the vagina in Type III, thus facilitating child birth, but does not involve reconstruction or replacement of the tissues removed in the original circumcision. The genitalia would not be returned to the pre-circumcision appearance or functionality, so women would still be considered circumcised, therefore eligible for inclusion. Women were excluded if they were accessing mental health services or receiving specialist care in relation to serious, pregnancy related physical health problems, or if it was known that the pregnancy was from forced intercourse or domestic violence.

Seven female participants were recruited from local maternity services; three were aged between18-25, three were between 26-30 and one between 36-40. The age when participants were circumcised ranged from just after birth to approximately 12 years of age. Three participants had undergone minor forms of FGM (Sunna) and four had undergone Type III; three had undergone reversal procedures (one in the research location) and one had a reversal planned. Four participants were Somalian, two were Sudanese and one was Eritrean; all were resident in the UK. Five participants were nulliparous and two were multiparous (expecting 3rd and 7th child); three were in the second trimester of pregnancy and four in the third trimester. Two participants spoke English, three were provided with Somali interpreters and two were provided with Arabic interpreters. To ensure consistency, the same two interpreters were used across interviews. Interpreters were provided to ensure inclusivity.

Materials

A semi-structured interview guide was developed, with reference to the aims of the study (Appendix B). A semi-structured interview was deemed the most appropriate because it allowed the researcher to flexibly engage and explore with participants, whilst keeping the research questions in mind. The guide was developed by the lead researcher in consultation with the research supervisor and the consultant within the maternity services.

Interpreters were briefed on the interview guide, prior to the interview taking place. The interview guide was piloted with the first two participants; no changes were made. Interviews were recorded using a digital voice recorder.

Design

The study utilised a qualitative methodology to attempt to understand the psychological and emotional needs of pregnant women with FGM. A qualitative approach was appropriate for the study given its exploratory nature.

Procedure

Participants were purposively recruited from local NHS maternity services, which could be accessed by anyone, to ensure inclusivity. Routinely, women with FGM are reviewed in the FGM clinic by a specialist midwife and consultant. The consultant gave women information sheets and discussed the study (Appendix C). Information sheets were provided in English, Arabic or Somali[4]. The women were asked in their next clinic appointment, or via telephone, to meet with the lead researcher. If in agreement, a mutually convenient meeting was arranged; interpreters were provided if needed.

[4] Translations were provided by reputable services and were back translated for accuracy.

During the research meeting, which took place in a quiet, private room in the maternity service, the information sheet was revisited and questions answered to ensure informed consent (Appendix D). The right to withdraw, without having their care affected was emphasised. Approximately 30 women were given information sheets; 10 women agreed to an initial meeting; three women did not want to participate. Seven women consented to be interviewed; interviews took place during the same appointment and lasted between 45 and 60 minutes.

To ensure confidentiality the lead researcher did not access the medical records of participants, and the consultant did not have access to participants' recordings or transcriptions. Five women required interpreters; interpreters were briefed before the research meetings and signed a confidentiality agreement (Appendix E). After the interview, participants were debriefed and offered the opportunity to participate in a focus group, in the future, to discuss and validate the themes. Participants were given a de-briefing information sheet (Appendix F); interpreters were also de-briefed. The digital recordings were transcribed by the researcher; each participant and people mentioned in their interviews were given pseudonyms.

Ethics

Ethical approval for the study was gained from the North West Committee, Liverpool Central of the National Research Ethics Service (NRES) (Appendix G).

Data Analysis

The principles of Thematic Analysis (TA) were utilised in the data analysis. Through its theoretical freedom, TA can provide a flexible and useful research tool, producing a rich, detailed account of data (Braun & Clarke, 2006). Different qualitative approaches were initially considered but were not used. The study aimed to explore individual experiences of FGM and pregnancy; as such, Grounded theory was not considered to meet the aims of the study, because of the focus on developing a theoretical understanding through the data analysis. The analytic process also needed to consider the diverse sample (different cultural backgrounds) and the use of interpreters, which would

require the researcher to make interpretations-based on translations. Interpretative phenomenological analysis (IPA) was also considered; however, because of the degree of interpretation involved in the method, which would be problematic given the mix of interviews with and without interpreters in the study, it was disregarded.

Holloway and Todres (2003) suggested researchers should make their epistemological position explicit. Epistemology (the theory of knowledge) is concerned with what knowledge is and how it can be acquired. Epistemology is considered important in qualitative research because it informs how one theorises meaning and what can be said about data (Braun & Clarke, 2006).

A realist approach assumes a singular objective truth waiting to be uncovered (Taylor & Ussger, 2001); a direct relationship between the world, our perception and understanding (Willig, 2001). In contrast, however, the relativist position emphasises the search for meaning; i.e., knowledge is constructed relative to a particular framework or standpoint (e.g. the individual, a culture, an era or a language). The relativist position emphasises description and the representation of reality through the meaning that participants attach to their experiences (Jones, 2010). The reported study aimed to explore the individual experience of FGM and pregnancy, using a more phenomenological approach. It is an attempt to understand the lived experience of those who are pregnant with FGM, to give pregnant women with FGM a voice within the maternity services. The study did not set out to prove or disprove hypotheses or to test theory; rather it sought to generate phenomenological data from which an understanding might be developed. It was therefore important that the process of interpretation remained embedded into what the women said in their interviews. In TA using a semantic approach, the themes are identified within the explicit or surface meanings of the data and what the individual has said or written.

TA can be used within a theoretical or inductive approach. A theoretical approach was disregarded because it relies on coding data based on relevant theory; in contrast, an inductive TA approach is driven by the data and the themes have strong links with the data. This has been

highlighted as a useful method for under-researched areas, like the one under investigation (Braun & Clarke, 2006).

Braun and Clarke (2006) provided a six phase approach for analysing data. Phase one began with the transcription of the audio recording by the lead researcher and familiarisation with the data. Some researchers argue that transcription is a key phase in analysis within interpretative qualitative methodology (Bird, 2005). Each individual transcript was repeatedly read through before beginning the process of hand-coding (Phase two) (Appendix H). The purpose of coding was to organise segments of the each transcripts into meaningful groups (Tucket, 2005). Phase three involved sorting the codes and collecting relevant coded data extracts into themes (Appendix I). The codes were distinct from the themes, which were broader level descriptions of the data and recognised meaningful repeated patterns across the entire data set (all of the transcripts). The themes of individual transcripts were represented visually in a thematic map (Appendix J).

In phase four the themes were independently reviewed and revised by the research supervisor. This phase involved two levels and individual transcripts were re-examined for incidents of supporting data for each theme. Some themes were expanded, others were discarded or collapsed and new themes generated and re-discussed. Level two of phase four involved examination of the validity of the themes across the entire data set. Searching for a theme was not a linear process, but an organic and on-going process. The themes were represented visually in a preliminary thematic map (Appendix K). The penultimate phase involved defining and naming the themes and sub-themes; the process included more than paraphrasing the data, moving towards interpretations of the essence of each theme and how this linked to the overall understanding in relation to the research question. The final stage was the production of the final report and thematic map.

Researcher's perspective

Qualitative researchers acknowledge that coding of data does not exist within a vacuum and so, researchers need to be explicit in disclosing their own values, assumptions and the impact it may

have on the interpretative process (Willig, 2008). Thus, it was important for the researcher to consider her perspective on FGM, the context in which it developed and the impact on the research process. In an attempt to own her perspective and the impact on the analytic process, the researcher's own perspective will be written in the first person.

Prior to commencing the research, I had very little knowledge of FGM and its possible impact; therefore I undertook some brief reading about FGM. Initially I found myself shocked and horrified at the thought of having my own genitals cut in what often seemed like barbaric circumstances. I found it hard to believe that women could experience such an event, without being psychologically changed. Over the process of conducting the research, within UK maternity services, there has been an ever increasing awareness of the negative aspects of FGM, including potential legal consequences to those involved. More specifically, within the NHS, safeguarding procedures and guidelines are in place to identify and prevent FGM (Department for Education, 2014). In conducting the research within maternity services, I had to adhere to local policy and procedures. In doing so I was also aware that as a white western woman conducting research within an NHS context, I may represent these negative views and this may impede the women from being open about their experiences.

Through continued reading, including personal accounts of FGM, however, I encountered different perspectives on FGM. I found it difficult to understand the perspective of women who felt psychologically enriched by FGM and who sought out FGM for themselves and their daughters. Without having had personal experience of FGM however, it was important to be open to different perspectives and be guided and respect the views of those who had. In light of this, the use of language within the research was carefully considered. For some the term FGM was too strong and potentially isolating, whilst others felt FGM reflected their experience of being mutilated. In attempting to remain balanced and open to the perspective of the participants, I adopted the terminology used by the women in the study. The use of language within the research was discussed further in Chapter Three.

In developing the interview guide, I framed questions without making assumptions about whether an experience was positive or negative. I also engaged in a process of reflection during the analytical process, carefully considering my own experience of pregnancy and birth, own values, ethnicity, culture and position towards FGM, and how this may impact on the themes. Through the reflective process, I have wondered whether, with such an emotive subject as FGM, it is at all possible to be truly impartial, therefore highlighting the need to be explicit about my own perspective on FGM.

Credibility checks

The transcript codes were checked, discussed and verified by the research supervisor and an independent researcher during the analytic process; the research supervisor checked the first two transcripts only. During phase five several discussions were held between the lead researcher and research supervisor to check the validity and credibility of the emerging themes, which contributed to the on-going process of developing the final thematic map. In areas of disagreement, the lead researcher referred to the original transcripts and previous discussions, and then made the final decisions regarding the analytical process. All the participants were offered the opportunity to discuss the preliminary themes; however, none of the participants wanted to.

Results

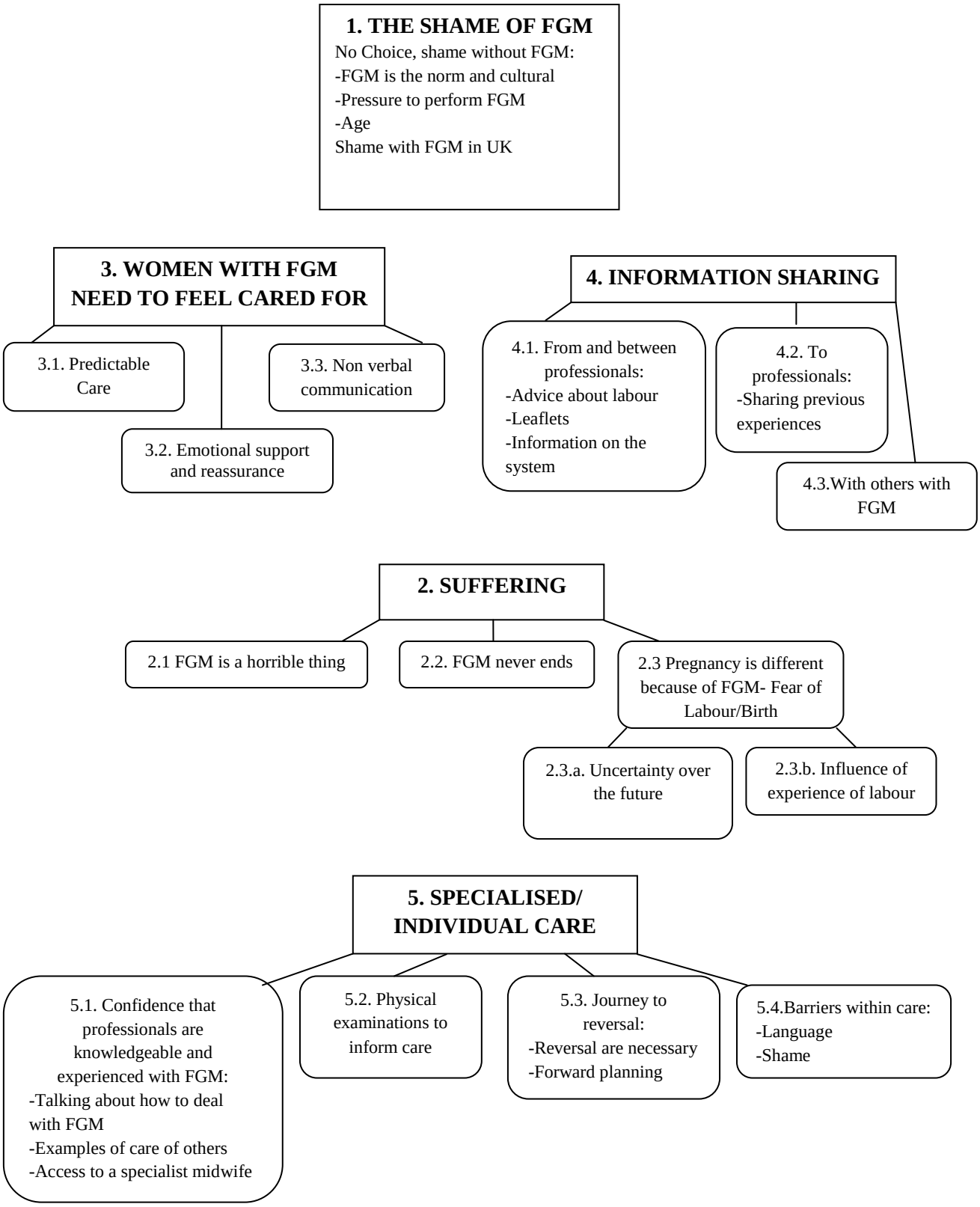
Five themes were derived from analysing the seven participant transcripts and visually represented (*Figure 1*). Table 1 shows the presence of each of the themes within individual transcripts.

Table 1

Presence of Qualitative Themes

	Participant						
Themes	One	Two	Three	Four	Five	Six	Seven
1 The shame of FGM	X	X	X	X	X	X	
2 Suffering	X	X		X	X	X	X
3 Women with FGM need to feel cared for	X	X	X	X	X	X	X
4 Information sharing	X	X		X		X	X
5 Specialised/ Individual care	X	X		X	X	X	X

Figure 1. Thematic map of the qualitative themes



Theme 1: The shame of FGM

The participants discussed the social context of their FGM procedure and the events surrounding it. The cultural expectations and the pressures to be circumcised left them feeling they had no choice but to be circumcised because of the shame and stigma *without* circumcision. All of the participants were resident in the UK, so had moved away from the community which had required FGM. This left some women feeling ashamed *because* of their FGM.

No choice, shame without FGM.

FGM is the norm and cultural.

All of the participants talked about FGM being part of the normal cultural practice of their native community. FGM was something everyone did and was not questioned, but was a fact of life.

> "I thought it was natural because all the neighbours, all my friends, everybody was doing it" (Participant 2, Line 3).

> "It wasn't happen only to me, it is Somali culture and everyone in the area has been done at that time and all the girls my age" (Participant 3, Line 22-23).

> "It is just because everybody practices it, in the community, so, er, our families have to practice it as well" (Participant 5, Line 36-37).

In addition to FGM being the normal cultural practice, it was also something that was required to feel a part of the community.

> "Ok, yes, it is two things, the first of all as I said before it's a cultural requirement, very strict cultural requirement, and if the girl is leave alone, how she is born and not do the circumcision, there is a stigma in Somalia, because the other girls of her age and other people, they attack her and they say you know, that girl she has not had the circumcision, what is wrong with her? Yeah, you know, that's very very stigma, that's one thing and the other thing

> is when a girl is grown up, you know the man they are looking for they woman who has a circumcision, otherwise they are not going to get married to that girl, that's the main reason." (Participant 6, Line 40-45).

Within the native communities, FGM appeared to be a 'requirement' because of the high social value placed in the practice. The practice was viewed as essential for protecting women from their own sexual desires, and preventing women seeking sexual relationships and having children outside of marriage. Women who followed their sexual desire were considered less desirable and therefore unsuitable for marriage.

> "I think, I think they believed that it was safe for the girls, to protect from mans, to protect from the man (small laugh) (3 seconds) this is what I was told" (Participant 1, Line 33-34).

> "Some people say, it's because when the girl might want to have the sex, in not the right way or whatever, out of the region, it's going to be, they don't do that thing...it's easier for her to sleep around or something, and some people say, that if you don't have that things done, you might not get married because, the man who is going to marry you, think you used to sleep around...he think this, that's what they think" (Participant 2, Line 32-36).

> "I am not sure I understand it but according to the community, er, we have always been told that this will reduce the desire, the sexual desire for the female so she won't have kids out of marriage...or she won't go for, follow her desire, out of the marriage...that's it...I don't want to bring shame to the family" (Participant 4, Line 24-27).

Pressure to perform FGM.

The high social value placed on FGM meant that people within the community were invested in maintaining FGM. Consequently, most of the participant's experienced pressure from members of

the community, their family or other girls their age. The pressure to be circumcised came from verbal and physical attacks, the promise of gifts, or from minimising the actual procedure.

> "The parent would tell you, you are going to have new clothes or new things and persuade you it's good, it's a good thing, you know. You don't know it hurts, they tell you, it's not hurt it's only a little touch, you're not gonna feel a thing or anything." (Participant 2, Line 3-6).

> "They will start to talk about that girl, she has not been circumcised, she is not a good girl, something like that" (Participant 5, Line 40-41).

> "We had a discussion and we asked each other, have you had the circumcision or not and if she, if the girl said yes I have, everyone proud, proud of her, but if not, people look at you like, why what is wrong with you…why you you, there is something, I don't know what you call it in English, but there's something called a buhyacab, that means you haven't had your circumcision and they call it, call you names...and you know the girl wants it to happen to her and everyone is eager to get it, get it done" (Participant 6, Line, 48-52).

> "OK, in terms of the physical abuse, it won't happen that often, that way, but it is usually verbally abuse, and people will say to her, or you haven't had a circumcision, why are you not having it, and you know the girl is scared that that will happen to them, and they know, you know, when they are 8, or 9 or 10 years of age, that's when, they won't wait anymore, they have to you know, ask their parents to have, or if they get the opportunity, they will get it done by themselves because they don't want to, you know the people targeting them" (Participant 6, Line 54-58).

No choice, shame without FGM.

The pressure to undergo FGM, and the high cultural value placed on the practice, left some women feeling as though they had no choice but to be circumcised, because without it they would feel ashamed and potentially stigmatised by their community.

"It's just everyone has it, everyone has to be done" (Participant 3, Line 27).

"Even if you're scared they're gonna cut you, you don't have a choice" (Participant 2, Line 6).

"Bring the shame means that for a female who is not married yet, to have a sexual intercourse with a male, this is because of her high desire of sexual intercourse or sexual relationships with males, so in order to reduce that desire they attempt to circumcise us, females, because you are not allowed to have children out of marriage, this will be shame" (Participant 4, Line 29-32).

Shame with FGM.

Within the UK, FGM is now widely discussed and publicised by the media. For one participant, her experience of being in the UK meant she felt different to other women who were uncircumcised. Consequently she felt ashamed of her circumcision, to the extent that she had denied having the procedure to others.

"It's not nice when they talk about it, they feel sorry for you and they feel sorry for the girls because of what's happened to them, but I feel like oh my god, I hope they wouldn't talk about it because I feel pain and it's very sad, I feel like I don't wanna talk about because of the shame, but I don't wanna tell them because then they will talk about me, you know they will say, this girl, she has had this done, oh my god, and then you will be the one who if different and everyone will talk, so I always say no I haven't had it done" (Participant 2, Line 116-121).

Theme 2: Suffering

Sub theme 2.1: FGM is a horrible thing.

For those who were old enough to remember being circumcised, the experience was described as being horrible, frightening and painful.

"It was a horrible thing; I felt it was a horrible thing" (Participant 1, Line 12).

"I was very scared...I was really scared and as soon as I was circumcised I started crying, I cried a lot and every time they washed the area with hot water, I start crying and I keep crying all day..." (Participant 4, Line 15-16).

"Circumcision is really bad, very bad, I wouldn't advise anyone to practise it on their daughters" (Participant 5, Line 16-17).

Only one participant talked of being happy around the time of her circumcision; she was eager to be circumcised because it was normal. This participant also talked about bullying from peers if you were not circumcised.

"I was happy, although I had a bit of pain, it was normal to me, and you know because I was happy because I had the circumcision." (Participant 6, Line 23-24).

For this participant, appraisal of FGM has having a potential benefit (being normal and accepted) was important in helping her adjust psychologically to being circumcised and protect against further psychological adversity by avoiding shame..

Sub theme 2.2: FGM never ends.

The women described the physical, emotional and relational consequences that they experienced because of their FGM, including flashbacks, emotional problems, menstruation problems and sexual and marital difficulties.

> "When, whenever I remember, I get flashbacks of it and I go, I feel it was a horrible thing" (Participant 1, Line 18).

> "I think that the people who did this to us, they didn't understand, you know the, you know that it can affect our health and they didn't understand, they didn't, you know mean, you know that they did a horrible thing to us , they told us it was better for us and it was safe for us (2 seconds) but they didn't understand how it would affect us in terms of our health, in terms of our emotions" (Participant 1, Line 28-31).

> "When you're weeing, it's different, sometime when you become this stage when you're having your period, it's so hard, very painful, even the period might not come out properly and the girls, they struggles, all the periods stay in you...you feel bad, bad and lots of problems...it's terrible" (Participant 2, Line 24-27).

> "You always feel that, oh my god, that there is something, this is something I can never get back" (Participant 2, Line 173-174).

> "I was concerned about the consequences of that circumcision ..so what will happen to me later on, and how much suffering I can take, up to this moment I am suffering, after my marriage..." (Participant 4, Line 35-36).

> "I mean that hardship that I have to take during the intercourse with my husband and it is another hardship when I have my periods...I suffer a lot...I am not relieved, so I am really tired...exhausted emotionally, especially that I am not having nice, sexual life, normal sexual life with my husband..." (Participant 4, Line 38-39).

For women who experienced ongoing difficulties FGM is not an isolated event occurring in childhood, but psychologically stays with them throughout their life, through adulthood and, as such, never ends. The ongoing physical difficulties act as psychological reminders of the feelings they experienced at the time of the circumcision and how they were permanently changed by the experience.

"The problem it never ends it is still with me now" (Participant 1, Line 92).

"The negative effect is not having a good life, a nice life, emotionally, physically and psychologically" (Participant 4, Line 58-59).

Sub theme 2.3: Pregnancy is different because of FGM- Fear of Labour and Birth.

The women described the experience of pregnancy as being different and harder because of FGM; without FGM, pregnancy would be an easier process.

"I believe that if I couldn't have done the female circumcision, it would be easier for me to be pregnant" (Participant 1, Line 38-39).

"Don't think about positives, for me, it is all negatives, only negatives" (Participant 4, Line 56).

"Yes, the pharonic circumcision is very hard during intercourse...you don't really feel it not until you get married and it even gets even worse when you get pregnant" (Participant 5, Line 48-49).

For many, the main difficulties with their pregnancy was the thoughts and feelings they experienced about how their labour would be different. The women here seemed to be suggesting that because they have experienced physical and emotional suffering in life, they have an expectation, or sense of inevitability of suffering in labour. Participant 6 said that "the problem is not the pregnancy but with the labour" (Line 101), a fear that was shared with almost all participants.

"I was really affected by the circumcision to the extent that now I am concerned about giving birth to my child" (Participant 5, Line 8-9).

2.3a: Uncertainty over the future

The fear of labour stemmed from both the uncertainty of how labour would go and the belief that their labour was going to be harder and more painful than uncircumcised women. The uncertainty expressed by the participants was around the impossibility of how the baby was going to fit through the reduced vaginal opening.

> "Although I am feeling, you know, thinking about what is going to happen next, it's not, not, I am still coping with it, sometimes I feel, gosh what will happen on the day [of the labour/birth] but I am still OK, managing it...Yes I am worrying about it" (Participant 1, Line 56-57).

> "I am happy, I want to have children, but I am scared, so late on I don't know what is going to happen, because when you are normal, when baby is born, I am sure it's easier, you will have a pain but it won't be like, how I think it's gonna be, I feel like, like oh my god, it's going to be hard, it's only a little tiny hole, how is a baby gonna fit, if they cut you, it's more pain again...I feel more scared, but I am happy that I am having a baby" (Participant 2, Line 38-42).

> "No, they reassured me, because at the beginning I was concerned, that my circumcision was really bad...so it will affect me in the labour" (Participant 4, Line 136-137).

> "It even gets even worse when you get pregnant, because there is no way you deliver the baby normally, they will have to open you up, unstitch you before, to remove that" (Participant 5, Line 49-50).

> "Yeah, the labour is always painful and stressful, but you know, I have had a bad experience in one of my pregnancy" (Participant 6, Line 135-136).

2.3b Influence of experiences of labour

The labour worries expressed by the participants were echoed by professionals and the evidence shared about the increased risk of complications they faced. They were also embedded in the

reality of witnessing the labour experiences of others with FGM or their own personal experience of labour.

> "So, after the examination they said we can help, you might have difficulties, some consequences, some complications, during the delivery process, so, it's better that we do something about it. So, for you, to make sure you end up with healthy baby and for the delivery to go smooth, we will decide for the C-section, caesarean section" (Participant 5, Line 6-10).

> "This is because I have noticed that my cousins, who are circumcised before me, who've had children before me, they give birth early, I noticed that they had hard labours, some of them resulted to surgery, some of them resulted to forceps, they suffered a lot" (Participant 4, Line 70-72).

> "Cos after the effects have been witnessed by the professionals, when those female who have circumcised before have their babies, they face horrible births, and sometime the children die, the baby dies during birth, during labour, or sometimes the mum dies during labour" (Participant 5, Line 43-46).

> "I had a baby in Somalia but this baby was die, because I had similar complications in labour" (Participant 6, Line 94-95).

Theme 3: Women with FGM need to feel cared for

All of the women in the study spoke positively about the care they have received in their pregnancy and felt cared for; most explained that they would not make any changes to their care.

> "I appreciate everything they did for me, because they have really taken care of me...so thank you very much for that" (Participant 5, Line 67-68).

> "I have had good care from this maternity services, er, you know, antenatal clinic" (Participant 6, Line 100).

Participant Six highlighted that for women with FGM *routine* pregnancy care is not enough because of what they have been through with their FGM and the lasting consequences of their experiences.

> " OK, the only thing I think about is, is the preparation of labour, because they need more care, a pregnant woman who has had a circumcision need more preparation, and more care for, because they are not like any other woman who has not had a circumcision" (Participant 6, Line 138-140).

Feeling cared for, for women with FGM, was not just about *what* care they received but *how* the care was delivered. Care being predictable, emotional support and reassurance, as well as non-verbal communication were all important features for women with FGM to feel cared for.

Sub theme 3.1: Predictable and responsive care.

All but one participant talked about the routine care they had received during their pregnancy; the regular appointments, treatment received at each appointment, especially in response to test results, and the plans for future appointments. From this there was a sense of participants knowing what to expect from their care and feeling prepared for the future, which may have been different from the care they would have received back home.

> "I had the scans...the regular check of the baby and blood tests, vitamin D tablets" (Participant 3, Line 44).

> "They get me the scans and check the baby, regularly, check the heart and the movement, and these things...they took a blood test from me, er, check my urine test and I have had regular appointments to check the baby and myself and if I need any medication, they give me, they prescribe me the medication as well" (Participant 6, Line 106-108).

> "Yeah, they care...they care for me well, every two weeks they see me, for myself and my own well-being and my baby...so they care for us...I am seen every two weeks now" (Participant 7, Line 56-57).

For one participant, predictable care meant the consistency of knowing who she was going to see i.e., having the same midwife for each of their appointments.

> "I would personally prefer to see one midwife, if I have an appointment, but that has not happened, when I have an appointment I see different midwives" (Participant 1, Line 107-108).

Predictable care in pregnancy, perhaps gave women a sense of certainty in a situation when there is so much uncertainty (Theme 2.3a). In foster a sense of certainty women perhaps felt more in control and able to manage their anxieties and fear.

Sub theme 3.2: Emotional support and reassurance.

Two participants explained that their care experience was good, because of the emotional support they had received, and without this support women may be left feeling scared about their future in pregnancy.

> "I am still a little worried now...but OK now I suppose...I will have supporter with me from Ruth[5] (link worker)" (Participant 2, 98-99).

> "No...they so far give me good support and before you get the baby, before you give birth, they will open you, before that and then afterwards it's going to be natural, not properly but it is better, I think this is enough support for me because I thought before that there is no support at all, and that's more scary" (Participant 2, Line 143-145).

> "Emotional support is important" (Participant 4, Line 129).

One participant talked about having space to think over the decision to have a reversal; she had no pressure from the midwife or doctor involved in her care. In doing so, care professionals acknowledged the difficult emotions involved in making decisions in pregnancy because of what the women had been through up to this point.

> "As I mentioned before, I was so scared at the beginning, but then they asked me to think about it, and then when I make my decision, I can come back, and let them know" (Participant 5, Line 101-102).

Care professionals also had the capacity to reduce the emotional suffering that women with FGM may have experienced, by offering procedures which could potentially eradicate or reduce the difficult physical consequences associated with FGM. This potentially puts professionals in a powerful position, but in this situation participants seemed to reflect that that power was used for their benefit.

> "She said, it's right you are circumcised, but we can help, we can offer you a surgery, to make the opening bigger, wider and then you won't suffer too much" (Participant 4, Line 12-124).

The participants' worry and anxiety over their labour and their babies were eased with reassurance, both verbally and through the care they had received.

[5] All names included in the quotes have been changed to ensure confidentiality.

> "I was worried thinking is she going to cut me straight away, I was like, confused, but when I meet her, I was like oh my god, when I met with her she explained to me what they are going to do, that this woman is professional and she will sort everything and you will be fine" (Participant 2, Line 95-98).

> "I had to undergo a surgery on the XXth June, and now I feel better, I feel more reassured about the delivery of my baby" (Participant 5, Line 19-20).

> "At that time, it was not, I was surprised and scared, not for myself it was for the baby, is this going to cause problems for my baby, is it going to harm my baby, all those questions I asked the midwife...it was surprise for me and concern, everything was about my baby" (Participant 7, Line 83-85).

One participant compared her care in the UK to the care she would have received at home, highlighting the difference in the care; this in itself was reassuring. With reassurance came hope that labour would be all right.

> "He says [participant's husband] don't worry, the hospital, the midwife, they know what they are doing, they will deal with you. There are like too many women like you who have given birth and they will deal with you. It's a good thing that you are here as well, they will open you before you have the baby...he gives me positive things about, he will say imagine you were back home and you didn't have all this help, you know they are going to look at you and see how you are, opening you, so he tell me don't worry" (Participant 2, Line 66-73).

Sub theme 3.3: Non-verbal communication.

The way that care professionals interacted on a human level was viewed as important for two participants to feel cared for, not only being professional, but also being 'nice' (warm) and understanding, which could be communicated through non-verbal behaviours.

> “That's what I feel like, I don't like talk about it sometimes...if they know, the services, that you are in a really bad state, if they are nice good people to talk to and they understand you and they do what they can to help you, like now, I have really good help” (Participant 2, 175-177).

> “They are very caring...they are always kind, nice, giving you smiley faces” (Participant 5, Line 110).

Theme 4: Information sharing

Information sharing was viewed as an essential part of FGM-related pregnancy care. It was felt that pregnancy was a good time to share information about FGM generally, but also to share specific information about labour processes and the treatment of FGM in pregnancy.

> "I think it is a good time to discuss the issues during the pregnancy" (Participant 1, Line 87).

> "I tell the midwife, she asked about if I have the FGM, she asked me and I say oh yes" (Participant 2, Line 92-93).

> "By the midwife's, no...the midwife's approach and way of talking wasn't scary, really, it was really normal, and they reassured me" (Participant 4, Line 120-121).

Information sharing was not a one way process but involved the exchange of information from, between and to professionals from women with FGM.

Sub theme 4.1: From and between professionals.

Information sharing from professionals was important for women to feel prepared, to know what to expect for their labours, especially for first time mothers. Some women also felt it was important to know more about their circumcision generally. This information came in the form of verbal advice from their midwife or doctor, but also in leaflet form.

> "Yes (3 seconds) I think lots of information needs to be given beforehand, because the pregnancy is there first baby and they haven't got much idea about what it is like and what is involved and they need to be given as much information (2 seconds) yeah" (Participant 1, Line 100-102).

> "Yeah, it was really good, I was with Sarah, the midwife, she take all the details, this was after I went to the emergency room, she explained everything to me, told me how it was going

to be, she took all the details, then she make me another appointment" (Participant 2, Line 87-89).

"You could give leaflets...more information about circumcision" (Participant 4, Line 129).

"I said before it is better to get good information from the woman beforehand and the interpreter" (Participant 6, Line 125-153).

One participant also valued the sharing of information between professionals through the storing of information electronically. This would make future pregnancy care easier, because professionals would be informed about her FGM and previous; but may also minimise the potential for shame, which some women can experience when talking about FGM (Theme 1: Shame of FGM).

"We will care for you, and they will open me and the next time, you are on the system, they already know what I am going to be like, how I come to them, what my situation is, and then that was OK because before, I was like, how are the doctors going to know, you know that I have this" (Participant 2, Line 125-128).

Sub theme 4.2: To professionals.

The sharing of information was a two-way process, an exchange between the women with FGM and the professionals involved in their care. The women in the study appreciated the opportunity to talk about their FGM and the impact this would have on their care.

"I like to talk about it, because I have had lots of bad experiences about it, so feel OK when they offering me to talk about it" (Participant 1, Line 84-85).

"Yeah, it was really good, I was with Susan, the midwife, she take all the details" (Participant 2, Line 87).

Additionally, those who had had previous birthing experiences wanted to be asked about those experiences. The exchange of information from women to professionals may shift the potential

power imbalance between patient and caregivers, giving the women a sense of control and empowerment over their pregnancy and labouring experience.

> "Before I had my first baby in the UK, I have been asked in the hospital if I have had the circumcision when I was younger, I told them yes, I have but I told them I have had other children as well, and they discussed with me how I delivered my children, they asked how was my circumcision, are you open or are you closed, reversal and things like that" (Participant 6, Line 110-113).

> "Yeah, for example, I am circumcised, but I don't have a major problem, but maybe other ladies will have major problems...so when they get those information from different people, of course that will help them, care for people who have been circumcised" (Participant 7, Line, 130-132).

Theme 3 highlighted the need for sensitive verbal and non-verbal communication, that can put women at ease, and may then foster an open dialogue in which women want to share information with their professionals.

Sub theme 4.3: With others with FGM.

One participant felt that talking to other women with FGM who had been through pregnancy and childbirth would be helpful. This participant was perhaps suggesting that feeling cared for in pregnancy may come from fostering hope that the outcome of pregnancy could be positive.

> "It is better to talk to the women who have had the female circumcision to talk with them, go through everything of their experiences, things like that" (Participant 1, Line 114-115).

Theme 5: Specialised/ Individual Care

Sub theme 5.1: Confidence that professionals are knowledgeable and experienced with FGM.

Talking about FGM and how to deal with it.

The women in the study discussed the importance of professionals having knowledge and experience of caring for other women with FGM in pregnancy and labour. For two participants, it was important that professionals acknowledge and understand how bad FGM had been for them and how bad the practice is in general. In acknowledging the potential difficulties associated with FGM, professionals can open up a dialogue with women.

> "For other people they need to know the bad side of it really...all the negatives about it" (Participant 4, Line 133-134).

> "They need to know that circumcision is really bad, bad practice" (Participant 5, Line 118).

The theme *Information sharing* was one way explained by participants that professionals demonstrated their knowledge of how to deal with FGM. This was demonstrated through their advice and information, including how they would manage their FGM in pregnancy and labour.

> "She said, it is right you are circumcised, but we can help, we can offer you a surgery, to make the opening bigger, wider and then you won't suffer too much" (Participant 4, Line 123-124).

> "How can I explain...all the advice they give, for example, when I give urine sample or blood, if they see any changes, they give treatment, the advice they give, it is very helpful, so all the care and the advice, and, er, the treatment (Participant 7, Line 106-107).

Poor care was synonymous with a lack of knowledge and experience of the professionals. For one participant with previous experiences of pregnancy and labour, the lack of experience and

knowledge by professionals, of how to deal with her FGM, was attributed as the reason for her labour complications, rather her FGM procedure. Investment in beliefs of FGM as positive experience may have shaped the appraisal and perception of care.

> "The only thing during the labour, the midwife cannot care for the woman properly, because this woman they have given this woman some kind of neglect, you know like, some woman got a third degree tear care because of the lack of knowledge, or care, or,er, sometimes they ignore it, or things like that, that is the only thing" (Participant 6, Line 155-159).

> "I had very, very complications, you know with the labour but finally the baby came out, but I had, er, damage...very deep tear, so, er that's why I said the second midwife was not good" (Participant 6, Line 92-84).

> "It would also be unhelpful if everyone in the healthcare services, if they didn't have a clue what is going on" (Participant 2, Line 186-187).

One participant also felt that positive experiences of current care and demonstrations of knowledge gave her confidence for her future pregnancy related care.

> "From the treatment I am getting, from the care I am getting now...gives me confidence in them, to rely on them, by the care they are doing" (Participant 7, Line 102-103).

Examples of care of others.

For one participant, knowledge and experience of professionals was demonstrated in examples of when professionals had successfully cared for others with FGM; therefore it was important for professionals to share good practice examples of their care of women with FGM.

> "I hear that they know already and they can deal with it, I ask also am I going to be, has it ever happen that the woman like me having, giving a birth properly and they say oh yeah" (Participant 2, Line 132-134).

Access to specialists.

Access to specialists in FGM was also perceived as a positive demonstration of the knowledge and experience of professionals.

> "Then she tell me that there is a midwife that is going to check me and see you, what kind of, how they are going to treat me...treat me differently so, so I meet with Rachel [specialist midwife], and then I met with Jane [consultant], so it was really good" (Participant 2, Line 93-95).

> "They asked me to be seen by the midwife who is specialised in the circumcision...so she will get to give her opinion…and that is what happened, I was examined by her" (Participant 4, Line 110-112).

Sub theme 5.2: Physical examinations to inform care.

Two of the participants did not undergo a physical examination of their genitals during their pregnancy; one participant was unsure if she had undergone an examination but she had undergone a reversal during her current pregnancy. One participant had undergone the *Sunna* type and had not experienced any physical complications since her circumcision, and the other participant had previous multiple births, reversals, re-infibulations (re-closing to restore Type III after childbirth); she was left *open* following her previous childbirth. Two participants explained that their physical examination was fine, and they had no problems.

> "Yes, I found them fine" (Participant 1, Line 71).

> "Interviewer: Can I ask how were you feeling before the examination? Participant 7: I have no problems. Interviewer: And what about during the examination? Participant 7: Nothing, the same" (Participant 7, Line 38-41).

Two participants experienced worry and initial fear over being physically examined, because of the uncertainty about what would happen; once explained, the worry and fear was eased. This suggested that any sense of uncertainty in pregnancy has the capacity to increase emotional distress.

> "First time I came down, I was worried thinking is she going to cut me straight away, I was like, confused, but when I meet her, I was like oh my god, when I met with her she explained to me what they are going to do" (Participant 2, 95-97).

> "I was scared...I was thinking that they are going to do a surgery on me... Interviewer: Do you feel there is anything which could have been done differently during your examination? Participant 4: No, I am happy with the check" (Participant 4, Line 104-107).

For women with FGM' physical examinations were seen as a necessary process to inform their future pregnancy care; for example, if they would need a reversal.

> "No, they reassured me, because at the beginning I was concerned, that my circumcision was really bad...so it will affect me in the labour...but after they have examined me, they reassured me, they said it is not so bad" (Participant 4, Line 136-138).

> "Like checking the woman beforehand, properly and if they need you know, if they need a reversal or cutting or something like that, they need good preparation beforehand" (Participant 6, Line 140-141).

Sub theme 5.3: Journey to reversal.

Reversals are necessary.

Much like with the physical examinations, for some women with FGM, the reversal procedure was seen as a necessary part of their pregnancy care. The women expressed mixed feelings before their reversal procedures and fear and worry over experiencing more pain, but also hope that

the procedure would facilitate a *normal* delivery and ease some of the physical complications experienced outside of pregnancy.

> "Bit scared...but again I don't know if it will be all right, I hope it will be all right...yes I am scared I wish they couldn't do this, but what can I do about it...nothing. I am scared that there is going to be pain, opening up again and I will feel the pain" (Participant 2, Line 103-105).

> "Because I've had it reversed I have more chances to deliver my baby vaginally, normally...so now I feel more relieved, I feel even better during the intercourse, unlike before" (Participant 5, Line 21-23).

Two participants did not require a reversal procedure, because of the type of circumcision they had experienced; however, one explained how she had hoped for an operation to resolve her physical problems.

> "If they had done surgery and opened me, the space, made a better space for me...this would be even better" (Participant 4, Line 103-104).

The fear of reversals was linked with the safety of the baby, and the fear was eased by reassurance, through careful monitoring throughout the procedure.

> "At the beginning I was reluctant to, to have the surgery, because I was pregnant" (Participant 2, Line 94).

> "I was so scared...they took care of the baby, the monitored him throughout, kept checking him, so I did not worry about him" (Participant 5, Line 91-92).

Forward planning.

For the women in the study, having the reversal procedure in pregnancy helped facilitate a *natural* (vaginal) delivery and to feel ready for when the baby came, and also avoid additional pain: "two pains together" (Participant 2, Line 152).

> "But I also think that it is a good thing that I am having this done now, before the baby comes, so that I will be ready to have my baby, I am happy about that" (Participant 2, Line 58-59).

> "When they open me up and when the baby comes, it's gonna be easier...I think about it in a positive way" (Participant 2, Line 62-63).

> "Now I feel better [after reversal], I feel more reassured about the delivery of my baby" (Participant 5, Line 19-20).

Without a reversal procedure, women were aware of the possible complications and the likelihood they would need a C-section.

> "If they won't open them and leave them the way they are and then when they are coming and giving birth, sometimes it can be late, you know or maybe you don't have transport and while you waiting give birth, if everything is blocked the baby can come, sometimes, if you are late or bus late, there is no one to help you and your are natural, you have better chance than the woman who has, you know...early planning, to leave the woman the way they are and say we will cut you at birth" (Participant 2, Line 181-185).

> "Prior to the surgery, they said, if you don't have it reversed, most probably you will end up with the C-section" (Participant 5, Line 20-21).

Sub theme 5.4: Barriers within care.

Language.

Language was seen as a huge potential barrier within the pregnancy care: language impacts on exchange of information between patient and professionals and therefore the confidence patients have of the professionals to care for them in their pregnancy and labour. One participant felt that appointments would be easier if the midwife spoke her language, whilst others were happy with having consistent use of an interpreter and written information in their own language.

> "I feel that, as I cannot speak the language, there are lots of gaps in the information, information missing" (Participant 1, Line 106-107).

> "It would be, I think, I feel that what would make things easier would be for me to see a midwife who could speak my language" (Participant 1, Line 110-111).

> "I think they are already doing really well and good information, really, good, when I read through papers, in my own language if I like and speaking to me, you can get interpreters, who can translate you, I think they already do really good thing, yeah"(Participant 2, Line 152-154).

> "You know sometimes there is a lack of understanding of the language and things like that, you know, this can be a barrier, the language barrier, although most of the time the women's hospital provides an interpreter for the woman who does not speak the language but that does not always happen and sometimes the woman she cannot speak the language and maybe this is her first baby and she has a circumcision and she does not have an interpreter, that can happen sometimes, but this kind of thing, you know the things can be a barrier" (Participant 6, Line 144-149).

Language may also be important in fostering a balanced relationship between women and professionals. If professionals do not provide interpreters for women it may be that implicitly they communicate to women that their opinions and view are unimportant; potentially leaving women, unwilling to communicate, isolated and fearful of the future.

Shame.

For one participant, the main barrier to services was the women themselves and their experiences. Women with FGM often come from communities where it may be viewed as shameful to seek help and assistance, in particular around FGM; this shame may prevent women accessing services or being able to open up about their FGM in pregnancy.

> "I think the barriers are only ourselves, the girls who have been done this, I feel, myself shame, shy to talk about it, because it's something, when you are another country where this never happens, you feel shy to talk about it, you just keep everything to yourself...that can be hard...but not the services, they only do something for you if they can, but I think most of girls, they shy and so say nothing, they feel its normal or maybe you're a bad parent or the family will tell you, oh god, its shame if you go to, go to the hospital or tell people or cut you open, what's the point that we do this thing for you...it's so crazy yes" (Participant 2, Line 162-167).

Discussion

The findings of the study will now be discussed in relation to previous research undertaken and the potential limitations of the study; clinical implications and future research will also be discussed. Five main themes emerged out of the analytical process; the themes related to how the women had made sense of their FGM procedure (*The shame of FGM*) and how this impacted on their experience of pregnancy (*Suffering*), as well as their experience of care professionals during their pregnancy (*Women with FGM need to feel cared for, Information sharing,* and *Specialised/Individual care*); the themes will be discussed in relation to the aims of the research.

Aim: What is it like to be pregnant and a women with a female circumcision, receiving care from maternity services in the UK? How is this linked with the personal experiences of FGM?

According to the participants, FGM was held in high regard by their native cultural groups and was *required* by the community (*The shame of FGM*). FGM was seen as method of protecting women from their sexual desires, thus increasing their desirability to males. This perhaps reflected the social position of women in their native communities, in which the value of females is in their marital eligibility. This left women feeling forced to undergo FGM to protect their female and family honour (Anderson, 2004), because without it they would be shamed and stigmatised by their community. It has been suggested that women may also gain self-esteem and establish a social identity by becoming a member of the circumcised group (United Nations Office for the Coordination of Humanitarian Affairs (U.N.O.C.H.A), 2005), which has been postulated as protective factor in the development of psychological difficulties (Applebaum, Cohen, Matar, Rabia & Kaplan, 2008).

FGM as means of sexual control of women and for marital eligibility is well documented in the research. Cameron and Rawlings-Anderson (1998) conducted research in Tower Hamlets in London. They found that uncircumcised women would bring shame by disrespecting their cultural traditions and customs; honour is dependent on women being circumcised (Rising daughters aware, 1998). The participants expressed various forms of pressure, from family, friends and the wider

community and a lack of choice but to undergo FGM, which reflected the desire to perpetuate FGM, because of its high social value. Research suggests that decisions about FGM are not made on an individual but a social level and women may feel powerless to decide against FGM (Dorkenoo, 1995; Jones, 2010), which perpetuates the practice.

One participant expressed feelings of shame *because* of her FGM, since moving to the UK. She appeared to be suggesting that the process of acculturation in the UK had exposed her to differing beliefs about FGM to those with whom she was raised. She had been left feeling different to other women and ashamed to have undergone a process which was viewed as negative and damaging by her new cultural group. A recent review undertaken by the author indicated that shame because of FGM is common amongst women who have migrated, because of the comparison between the self and what is viewed a culturally normal (see Chapter One, Literature Review). Bengston & Baldwin (1993) suggested that some women can question themselves, and feel insecure and confused at the realisation that they are not just a minority but are also considered mutilated and traumatised. As such, women in the UK with FGM may be particularly vulnerable to feelings of shame; this highlights the need for professionals to be sensitive in their care giving approaches because of the potential for shaming experiences if care is mismanaged. This may further highlight the need for specialist services for women with FGM, especially during a vulnerable time like pregnancy.

The participants described their FGM procedure as a painful and frightening experience, which had remained with them throughout their life through their ongoing physical and emotional problems (2.2 *FGM never ends*). Consequently, there was a sense of the women experiencing their pregnancy (and labour) as more difficult than uncircumcised women. The women appeared to be suggesting that their FGM had meant suffering through life, and because pregnancy and labour are a part of life, this would also mean suffering (*Suffering*). Peprah (2009) explained the multiphase trauma of women with FGM: for some the trauma begins with the cutting experience, but then occurs again with the first experience of intercourse and then with childbirth. Maternity staff asking women about their FGM experience and their long term consequences may facilitate a dialogue in pregnancy,

through acknowledging the pain and suffering they had endured in life. The sub theme 5.1 (talking about FGM and how to deal with FGM) suggested that women need professionals to acknowledge how bad FGM has been for them to facilitate open communication. D'Entremont et al. (2013) speculated that a culture of silence amongst professionals regarding FGM may lead to feelings of shame and fear in circumcised women.

The suffering in pregnancy that women in the study had endured was related to the fear and anxiety of labour. Labour was expected to be harder and more painful and there was disbelief about how the baby would come out. Lundberg and Gerezigher (2006) explored retrospective accounts of labour in Eritrean women in Sweden; they found themes around fear and anxiety in relation to labour and the expectation of extreme pain and complication in both life and labour. The author's study is, however, the first conducted within the UK which has demonstrated the profoundness of the suffering of pregnant women with FGM at the time of being pregnant.

The adverse outcomes for women with FGM in childbirth, including C-sections, tears, episiotomy, blood loss and foetal problems are well documented (Al-Hussaini, 2003; Chibber, El-Saleh & El-Harmi, 2011; Small et al., 2008; WHO, 2006; Wuest et al., 2009). The worries of women with FGM in the current study were echoed in their experiences with professionals and women being witnesses to the experiences of others (2.3b *Influence of experiences of labour*). The WHO (2011) and the UNOCHA (2005) suggested that hearing about other women's difficulties and previous bad experiences can put women at risk of anxiety and fear of giving birth; in contrast, however, one participant wanted to hear about positive birthing experiences of women with FGM, as this may give hope that positive outcomes are possible if care is managed effectively.

This highlights the need for professionals working in maternity to be sensitive to the cultural context and the experiences that women with FGM have been through to the point of being pregnant. This may be particularly pertinent when exploring the need for reversals; asking women about their personal beliefs and cultural context may help professionals empathise and support women in the complex decision making processes; for example, their desire to have relief from physical problems

coupled with feelings of guilt or betrayal at *reversing* a cultural practice. Braddy and Files (2007) and Jones (2010) both support this idea in women who were not pregnant but seeking reversals.

How do circumcised women experience the physical investigations associated with pregnancy?

The experience of physical examinations formed part of the theme *Specialised/Individualised care.* Most of the women in the study had experienced physical examinations of their genitals. Only two women reported that they had initially felt worry over the examination, because they were unsure what to expect. This finding is contradictory to the evidence regarding how women experience the physical examinations (Pereda & Perez-Gonzalez, 2012; Widmark et al., 2010). The women in this study reported that physical examinations were explained well (which eased the initial anxiety) and were viewed as part of the *Specialised/ Individual care* that women with FGM need. Physical examinations were seen as necessary to inform future pregnancy related care; e.g., the need for reversals. This suggests that physical examinations do not need to be anxiety provoking, or potentially traumatising, if women are reassured, well prepared and given a clear rationale why the examinations are needed.

How pregnant women with FGM experience the health professionals providing their care; for example, midwives, doctors and perinatal mental health workers (including clinical psychology), during their pregnancy.

The themes of *Women with FGM need to feel cared for*, *Information sharing* and *Specialised/Individual care*, were related to the aim of understanding how women experienced the health professionals providing their care. For some, feeling cared for in pregnancy meant predictable care (planned, responsive and the same midwife); for others this reflected the emotional support and reassurance and the humanity of their midwife (non-verbal behaviours). Chalmers and Omer-Hashi (2000) supported the findings about the importance of the approach taken to be important; they found women with FGM found maternity care workers in Canada to lack sensitivity and this was expressed in verbal comments but also in non-verbal behaviours (looks of disgust). For some, emotional support

in the study was linked with the capacity of midwifes to relieve the emotional distress of their physical problems by offering *Specialised care* (theme five), namely reversal procedures. One woman also appreciated the time and space to think over decisions, to have a reversal without pressure.

The theme of *information sharing* (4) appeared to be linked with the need for professionals to demonstrate their *knowledge and experience with FGM* (5.1); by professionals sharing information about how they have and would care for women with FGM, women could feel more confident to manage their worries about labour. The sub themes of sharing information to professionals (4.2), perhaps reflected the desire of women to share their experience and so professionals could learn from the less positive experiences of care; this appeared to empower women to manage their labour. The willingness of professionals to listen to women perhaps also contributed to feeling of the responsiveness and individualised care (theme five & sub theme 3.1).

Previous studies have highlighted that women with FGM have experienced health professionals in the UK and abroad as unknowledgeable about FGM (Chalmers & Omer-Hashi, 2000; Lockhat, 2004; Lundberg & Gerezgiher, 2006; Vangen et al., 2004) and that better training may be needed for healthcare professionals (Whitehorn, Ayonrinde & Maingay, 2002). This appears to support the findings in the current study: because the women experienced the professionals as knowledgeable, they felt more confident in their care, whereas lack of knowledge about FGM and how to care for women may be a barrier to services (Jones, 1010). This again highlights the need for specialist FGM services both in pregnancy and more generally for health related problems.

The women in the study identified language as a potential barrier in maternity care (sub theme 5.4): one participant highlighted the need for consistent use of interpreters and another participant expressed a preference for a midwife who spoke her language. Language has been raised as a potential barrier consistently across research findings in the retrospective accounts of pregnancy and childbirth (Murray et al., 2010). As highlight by the current study, overcoming language barriers is important because of the explicit verbal information that can missed but is equally important in

implicitly communicating the message that women's views are important and care is being done with not too.

Methodological Limitations

The findings were evaluated in terms of the methodological limitations, relating to different aspects of the study.

Design.

An inductive TA approach from a relativist perspective was used to explore how women made sense of their FGM experience, the impact on pregnancy and their experience with maternity professionals. The data and analysis were discussed and validated at various stages of the process and the use of direct quotes further validates the interpretation made. Nonetheless, the researcher was unable to validate the themes with the participants themselves. This process may have been helpful in ensuring that the themes were an accurate reflection of the participants' own experiences.

Interviews.

The location of the study was carefully considered to facilitate inclusivity and access to interpreters and to ensure participants were familiar with their environment. It is possible, however, that conducting the research interviews in a room within the maternity services may have impacted on the participants' comfort and willingness to be open and critique their care. For future research it may be helpful for participants to be given a choice in the location of research activities.

Sample.

Participants were recruited from within a specialist FGM clinic; therefore their views on the care they received may not represent the wider of view of women with FGM accessing general maternity services. It may be useful to repeat the study within an area in which women may not have

access to a specialist clinic; however, recruitment issues may impede this. The findings do, however, suggest that positive experiences of care may be linked with access to specialist services.

In recruitment, approximately a third of women declined to participate; therefore the sample size was relatively small. It was been suggested that 12 participants is ideal for thematic analysis; however, it is possible to construct themes from fewer participants (Guest, Bunce & Johnson, 2006). The research was conducted within a service (and a society) which is increasingly communicating negative views about the practice of FGM; therefore, it is possible that women who also experienced FGM negatively were more willing to participate. The accounts may thus be potentially biased towards finding negative consequences of FGM, an issue highlighted with previous research. The researcher did, however, attempt to manage potential bias by using open language and asking participants for both positive and negative experiences of FGM and care in pregnancy.

It would, however, be interesting, but perhaps impossible, to explore the reasons why women refused to participate; for example, whether these refusals reflected a positive experience of FGM, pregnancy and their care, or whether talking about FGM would be too painful? The theme of s*hame of FGM* also leads to the question of whether the shame of talking about FGM and the culture of silence meant that women felt unable to participate.

Clinical implications

1. For the participants, *how* care was delivered was as important as *what* care was delivered; professionals being kind, caring and consistent (both verbally and non-verbally) helped women feel cared for.

2. Women may respond to a sensitive, open and non-judgemental dialogue about their personal experience of FGM and the subsequent consequences. There may be the potential for women to experience shame if professionals shy away from talking about FGM.

3. Professionals need to have and demonstrate their knowledge about FGM and pregnancy-related FGM care, which may be gained through training. Without sufficient training,

professionals may lack confidence to engage in discussion about FGM. There may be opportunities for women with FGM to be involved in training, and research suggests that user-led training may be helpful (Jones, 2010).

4. Women also need professionals to understand the potential for shame, their likely worries and their experiences of suffering in pregnancy.Alongside the knowledge and experience needed to care for women with FGM, these factors highlight the need for specialist services.

5. Physical examinations need to be introduced to women in a careful and sensitive way, offering reassurance and a clear rationale and explanation. The same approach could be used with the discussion of reversal procedures. The women in the study felt supported in this decision making process: they were given time and space and were not pressured into the process, which gave them a sense of control.

6. One participant also suggested that she may benefit from being able to talk to other women with FGM who have had positive birthing experiences. This could be facilitated with service-user led support group; however, this would need careful consideration, as some women may experience anxiety and worry in relation to hearing negative childbirth narratives.

7. The use of interpreters within health services needs to be consistent and, where possible, female. Also where possible, it may be helpful for the midwife to speak the same language as the woman.

8. The women in the study felt cared for because of the predictable and consistent care they had received. It was suggested that having the same midwife would help women feel cared for; however, this is not always possible within busy maternity services. It may thus be helpful for a woman with FGM to have a limited circle of midwives giving their care.

9. Some women in the study also reported current experiences which may indicate they were experiencing symptoms of PTSD. This highlights the need for professionals working with

women with FGM in their pregnancy to be aware of the potential for psychiatric symptoms and for women to have access to psychological therapy services.

10. In addition to providing therapeutic services to women directly, there is also a potential role for clinical psychologist working within maternity services to provide training for other professionals in the screening for psychological difficulties.

Implications for future research

The women in the study generally experienced professionals as knowledgeable and confident in their ability to deliver their maternity care; however, it may be interesting to explore the perceptions of midwives on FGM related care, in particular within the context of a specialist FGM clinic. Much of the research in the UK has focused on auditing service outcomes against standards, with little attention on the experience of maternity care workers in FGM services.

The women in the study were interviewed during their pregnancy: for future research it may be interesting to follow women up after childbirth, and to explore how their expectations and care experiences in pregnancy impacted on their actual birthing experience.

Conclusion

The current study is the first to examine the experience of pregnancy for women with FGM, and thus has added to the wider knowledge of how pregnant women with FGM experience their pregnancy and their maternity care. The study has captured the profoundness of the suffering of women with FGM and has identified the key aspects of specialist FGM maternity services, in which professionals would be well trained and experienced in supporting women to manage the potential emotional suffering of FGM in pregnancy.

References

Amereskere, M., Borg, R., Frederick, J., Vragovic, O., Saia, K., & Raj, A. (2011). Somali immigrant women's perceptions of caesarean delivery and patient-provider communication surrounding female circumcision and childbirth in the USA. *International Journal of Gynaecology and Obstetrics, 115*, 227-230.

Al-Hussaini, T.K. (2003). Female genital cutting: Types, motives and perineal damage in labouring women in Egypt. *Medical Principles and Practice, 12*, 123-128.

Anderson, B. A. (2004) *Reproductive Health: Women and Men's Shared Responsibility.* Massachusetts, USA: Jones and Bartlett Publishers.

Apgar, V. (1953). A proposal for a new method of evaluation of the newborn infant. *Current Researches in Anesthesia and Analgesia*. *32*(4), 260–267.

Applebaum, J., Cohen, H., Matar, M., Abu Rabia, Y., & Kaplan, Z. (2008). Symptoms of posttraumatic stress disorder after ritual female genital surgery among Bedouin in Israel: Myth or reality? *Primary Care Companion to the Journal of Clinical Psychiatry, 10*(6), 453-456.

Bengston, B. & Baldwin, C. (1993). The international student: Female circumcision issues. *Journal of Multicultural Counselling & Development, 21*(3), 168-173.

Bird, C. M. (2005). How I stopped dreading and learned to love transcription. *Qualitative Inquiry, 11*(2), 226-248.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brown, E., Carroll, J., Fogarty, C., & Holt, C. (2010). "They get a c-section...they gonna die": Somali women's fears of obstetrical interventions in the United States. *Journal of Transcultural Nursing, 21*, 220-227.

Cameron, J. & Rawlings-Anderson, K. (1998). Circumcision, culture, and health-care provision in Tower Hamlets, London. Gender & Development, 6(3), 48-54.

Chalmers, B., & Omer-Hashi, K. (2000). 432 Somali women's birth experiences in Canada after early female genital mutilation. *BIRTH, 27*(4), 227-234.

Chibber, R., El-Saleh, E., & El Harmi, J. (2011). Female circumcision: Obstetrical and psychological sequelae continues unabated in the 21st century. *The Journal of Maternal-Fetal & Neonatal Medicine: The Official Journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians, 24*(6), 833-836. doi:10.3109/14767058.2010.531318

d'Entremont, M., Symthe, L., & McAra-Couper, J. (2013). The sound of silence: A hermeneutic interpretation of childbirth post excision. *Health Care for Women International, 35*(3), 300-319.

Department for Education, Home Office. (2014). *Multi-agency practice guidelines: Female genital mutilation*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/380125/MultiAgencyPracticeGuidelinesNov14.pdf

Department of Health. (2009). *Improving access to psychological therapies. Perinatal: Positive practice guidelines*. London: HMSO.

Department for Education and Skills. (2004). *National service framework for children, young people and maternity services.* London: HMSO.

Dorkenoo, E. (1995). *Cutting the rose. Female genital mutilation: The practice and its prevention.* London, England: Minority Rights Publications.

Dorkenoo, E., Morison, L., & MacFarlane, A. (2007). *A Statistical Study to Estimate the Prevalence of Female Genital Mutilation in England and Wales*. London, England: Foundation for Women's Health, Research and Development (FORWARD).

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Family Health International, 18*(1), 59-82.

Holloway, I., & Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research, 3*(3), 345-357.

Jones, A. (2010). *Working psychologically with female genital mutilation: An exploration of the views of circumcised women in relation to better psychological practice* (Doctoral dissertation). Retrieved from British Library EThOS. (ethos.015941094.)

Lockhat, H. (2004). *Female genital mutilaton. Treating the tears.* England: Middlesex University Press.

Lundberg, P. C., & Gerezgiher, A. (2008). Experiences from pregnancy and childbirth related to female genital mutilation among Eritrean immigrant women in Sweden. *Midwifery, 24*(2), 214-225.

Murray, L., Windsor, C., Parker, E., & Tewfik, O. (2010). The experiences of African women giving birth in Brisbane, Australia. *Health Care for Women International, 31*(5), 458-472.

National Institute for Health and Clinical Excellence.(2007). *Antenatal and postnatal mental health: Clinical management and service guidance*. London: NICE.

Nicholson, P. (2010). What is 'psychological' about 'normal' pregnancy? *The psychologist, 23*(3), 190-193.

Paliwal, P., Ali, S., Bradshaw, S., Hughes, A., & Jolly, K. (2013). Management of type III female genital mutilation in Birmingham, UK: A retrospective audit. *Midwifery, 30*, 282-288.

Peprah, S.Y. (2009). *Clinical consideration for mental health working with women who have undergone female genital cutting* (unpublished doctoral dissertation). Alliant International University, Los Angeles, California.

Pereda, N., Arch, M., & Pérez-González, A. (2012). A case study perspective on psychological outcomes after female genital mutilation. *Journal of Obstetrics & Gynaecology, 32*(6), 560-565.

Rising Daughters Aware (1998). Rising Daughters Aware: The Stories. http://www.fgmnetwork.org/reference/biblio.php (Last accessed on 27.12.2014).

Slade, P., & Cree, M. (2010). A psychological plan for perinatal care. *The Psychologist, 23*(3), 194-197.

Small, R., Gagnon, A., Gissler, M., Zeitlin, J., Bennis, M., Glazier, R.H., Haelterman, E., Martens, G., McDermott, S., Urquia., M., & Vangen, S. (2008). Somali women and their pregnancy outcomes postmigration: data from six receiving countries. *BJOG: An International Journal of Obstetrics and Gynaecology, 115*(1), 1630-1640.

Straus, L., McEwen, A., & Hussein, F.M. (2007). Somali women's experience of childbirth in the UK: Perspectives from Somali health workers. *Midwifery, 25*, 181-186.

The Female Genital Mutilation Act, c.31, (2003).

The Prohibition of Circumcision Act, c.38, (1985).

Tuckett, A. G. (2005). Applying thematic analysis theory to practice: A researcher's experience. *Contemporary Nurse, 19*(1-2), 75-87.

United Nations Office for the Coordination of Humanitarian Affairs (UNOCHA.) (2005). *Razor edge documentary: The controversy of female genital mutilation*. Produced by IRIN, a project of the UNOCHA.

Vangen, S., Elise, R., Johansen, B., Sundby, J., Traeen, B., & Stray-Pedersen, B. (2004). Qualitative study of perinatal care experiences among Somali women and local health care professionals in Norway. *European Journal of Obstetrics & Gynaecology and Reproductive Biology, 112,*

Whitehorn, J., Ayonrinde, O., & Maingay, S. (2002). Female genital mutilation: cultural and psychological implications. *Sexual and Relationship Therapy, 17(2),* 161-170.

Widmark, C., Leval, A., Tishelman, C., & Ahlberg, B.M. (2010). Obstetric care at the intersection of science and culture: Swedish doctors' perspective on obstetric care of women who have undergone female genital cutting. *Journal of Obstetrics and Gynaecology, 30*(6), 553-558.

Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method.* Open University Press. UK.

Willig, C. (2008). *Introducing qualitative research in psychology: Second edition*. Open University Press. UK.

World Health Organisation (2000). *A systematic review of the health complications of female genital mutilation including sequelae in Childbirth.* Geneva, Switzerland: World Health Organisation. Retrieved from http://www.who.int/gender/other_health/en/systreviewFGM.pdf

World Health Organisation (2006). Female genital mutilation and obstetric outcome: WHO collaborative prospective study in six African countries. *The Lancet, 367(9525),* 1835-1841.

World Health Organization. (2008) *Female Genital Mutilation. Fact Sheet Number 241.* www.who.int/mediacentre/factsheets/fs241/en/ (Last accessed: December 27 2014).

Wuest, S., Raio, L., Wyssmueller,D., Mueller, M.D., Stadlmayr, W., Surbek, D.V., & Kuhn, A. (2009). Effects of female genital mutilation on birth outcomes in Switzerland. *BJOG An International Journal of Obstetrics and Gynaecology, 116,* 1204-1209.

Zenner, N., Liao , L.M., Richens, Y., & Creighton, S.M. Quality of obstetric and midwifery care for pregnant women who have undergone female genital mutilation. *Journal of Obstetrics and Gynaecology, 33*, 459-462.

Chapter Three

Extended Discussion

Introduction

This chapter is divided into three parts: an extended discussion bringing together the findings of Chapters One (literature review) and Two (empirical paper); a lay person's summary of the research reported in Chapter Two and a research proposal for a future project.

Extended Discussion

The extended discussion will explore the findings of the qualitative synthesis in Chapter One and the results from Chapter Two and discuss these in relation to the research and theory. Personal reflections will also be made in relation to conducting research within the field of FGM. The discussion will focus on all six themes from the qualitative synthesis of Chapter One (emotional responses, FGM is with you for life, mind and body connection, loss, shame and guilt and protective factors) and the first two themes from Chapter Two as these were linked with the general psychological and emotional consequences of FGM, and not on the care experiences in pregnancy.

Examining the findings from the literature review and the empirical paper highlighted the significance of shame in the experiences of women with FGM (Review theme five; empirical paper theme one and 5.4). Both chapters reported a mixture of positive and negative feelings *following* FGM. The positive feelings in both synthesises were happiness and pride in FGM, which was linked with the wider cultural beliefs and the community expectations that FGM was needed. Being circumcised meant women avoided stigmatisation, bullying and shame in their native cultures. Feelings of shame (and guilt) are associated with being negatively evaluated (either by the self or others) because one has failed to meet the standards and norms of what is right, good, appropriate or desirable (Lewis, 1974). Shame may be a violation of cultural and social values and arises when one's own deficits are exposed to others, resulting in the negative evaluation of others (Benedict, 1946).

This is particularly pertinent for women with FGM, like the women who took part in the study reported in Chapter two, who have migrated from their native community and become exposed

to a new host culture and beliefs. For example women living in the UK where FGM can be viewed as abusive, damaging and traumatising. Within the literature review and empirical paper there were references to women hiding their FGM status for fear of being judged or feeling different to others. To understand the long term psychological impact of FGM it is important to consider the process of acculturation and that women may experience shame because they believe they have done something wrong (undergoing FGM or not), either in their own eyes or, more likely, in the eyes of others (Wong & Tsai, 2007). Women's rejection of FGM for their daughter's may reflect integration into a new cultural group and a change in their attitudes and beliefs from their origin culture.

The theme of *Loss* from Chapter One may also reflect the impact of acculturation on the psychological consequences of FGM. The women reflected that they were permanently changed by their FGM and through assimilation and integration into a new cultural group, came to realises that they may never be like *other women*. As discussed, feeling different to other women maybe a source of shame; this may impact on a woman's self esteem and self confidence (Theme three, Chapter One). The review and one participant in the empirical study believed shame could be a barrier to accessing services because of the reactions of others including healthcare professionals regarding their FGM, leading to social withdrawal and delays in seeking help. Thus the way that FGM is talked about in healthcare settings is particularly important. Jones (2010) indicated that women wanted professionals to understand the practices of FGM and facilitate conversations about FGM, responding in a sensitive and non-judgemental manner, which minimised the potential for shame. The findings discussed in Chapter Two also highlighted that the importance of healthcare professionals being culturally sensitive in the process of offering reversals for women with FGM. For some women, reversals may not just be about minimising the damage sustained during their FGM procedure, but may also be symbolic of rejecting their native cultural practices.

The review reported the negative psychological and emotional consequences that can follow FGM (1.3: Current distress, 2: FGM is with you for life and 3: Mind and body connection). In the review current emotional distress (1.3) was similar to the feelings at the time of being circumcised,

including helpless, shock and pain; this was also echoed in the empirical paper (2.1: FGM is a horrible thing).Women reported sadness and depression in response to memories of their FGM procedure, and avoidance of triggers to bad memories, flashbacks or nightmares of their circumcision. The review theme FGM is with you for life expanded on the understanding of the consequences, suggesting they can occur immediately following FGM or during significant life events (puberty, marriage and pregnancy). The qualitative evidence indicates that women may experience psychological trauma directly following their FGM or later in life.

From her study of women with FGM in the UK, Lockhat (1999) has developed a predictive model to explain the development of clinical psychopathology post-circumcision. The model suggests that the women with s*evere f*orms of FGM and those with post circumcision complications were likely to go on to develop PTSD; however this progression was mediated by a number of factors (positive or negative recollections of their FGM procedure, community support and use of anaesthetic during their procedure). Lockhat's model (1999) suggests that women with milder forms typically did not experience PTSD.

The evidence from Chapter One and Two does not support the assumption of the model, that women with milder forms of FGM do not experience trauma; however this assumption may be linked with likelihood that women with more severe forms are more likely to experience ongoing physical problems. Theme three from Chapter One indicated that women with FGM may experience their body and mind as connected and therefore the physical experience of the body can impact on the emotional experiences (3.1: Physical problems feed the psychological*)*. Thus the physical pain experienced in life can have an emotional impact or be a trigger for psychological trauma and distress.

The empirical paper also highlighted the possible longevity of the consequences of FGM (2.2: FGM never ends) and the connection between physical and emotional experiences. Women reported their FGM as enduring throughout their life, through their ongoing physical complications. For example, the pain experienced during menstruation and intercourse was described as a hardship and an emotional burden. Participants also reported *suffering* (theme 2.3) during pregnancy, because of

the fear and worry over anticipating pain and complications in labour. The evidence from Chapter one and two suggest that it is the ongoing physical consequences which may be more pertinent in understanding how trauma may develop rather than the type of FGM experienced.

Raya (2010) however suggest that the psychological and emotional consequences of FGM can be understood by drawing on the literature about the impact of chronic childhood maltreatment and neglect and re-conceptualisation of these experiences as Complex Developmental trauma. Raya (2010) suggests that complex trauma is a mind-body-brain (neuronal) experience that alters a child's biology, sense of self, consciousness, and relational attachments. In Chapter One, Theme Loss there was some evidence that women experienced a loss of trust in significant others as result of their FGM because it was the women closest to them (mother, grandmother or aunt) who instigated their FGM. The theme went onto to suggest that women found it difficult to trust others after this and their affected their long term relationships. The findings of Chapter One and Two suggested that women experience their physical and emotional experiences as interconnected. There is a paucity of research into the psychoneurobiological effects of FGM however this may be an interesting area for future research and may have potential implications for the therapeutic interventions offered to women with FGM.

There was some evidence in Chapter One and Two to suggest that the events surrounding the FGM procedure is important in shaping women's appraisals of the FGM and their conceptualisation of the procedure as traumatic. For example if women were prepared for what was going to happen and if steps were taken to minimise the physical pain, through the use of anaesthetic (Lockhat, 1999) then they may be less likely to perceive the procedure as negative or traumatic and this may serve a protection function against future trauma and psychological distress. This may partially account for the lack of long term psychological and emotional consequences found in some women with FGM.

Conclusion

Examining the findings of Chapters One and Two indicated that there was evidence to suggest that women with FGM in the UK may be vulnerable to feelings of shame, and subsequent

psychological and emotional distress. The responses and approach of others, especially health professionals, which facilitates an open dialogue, is important in mediating potential shame, thus impacting on current care experiences and future help seeking behaviours. Women with FGM may also experience psychological trauma, immediately following or in the long term as a result of their FGM. It is important for clinicians to consider the events surroundings the FGM procedure, as this may be important in understanding their psychological difficulties.

Personal reflections on FGM research

The researcher reflected throughout the research process about the use of language within the FGM research. Initially when starting the research process the researcher became familiar with the classification system for the Types of FGM and the different terms used for the different types of FGM. When considering her own research it seemed arbitrary to distinguish between the types of FGM, because of personal feelings that any cutting to the genitals would surely lead to psychological problems.

The researcher noted however that within her own work, as well as in the works of other researchers and individual accounts the use of descriptions such as *minor* and more *extreme* forms of FGM. Within participant accounts from the current research, participants made reference to Sunna, being the easy/easier form of FGM and Pharonic being more complicated. The development of the classification system is perhaps reflective of the way the *lay person* may distinguish between the different forms of FGM. It may also reflective of the historical focus within FGM research towards the physical rather than psychological aspects of the FGM and the human nature to organise and categorise experiences.

When exploring the psychological impact of FGM for an individual it is important to consider the use of the language very carefully. The use of terms such as *minor* or *easy* are perhaps reflective of extent of the physical damage, but in no way reflect the psychological impact. In the current research it was evident that some women, who had experienced *physically* less extensive FGM, were

still psychologically and emotionally affected by their FGM. So, for future research considering the possible psychological impact of FGM, the Type of FGM may be less important than the individual journey and experience with FGM.

Lay Person's Summary

The summary below formed the feedback of the empirical study, given to the maternity staff working in the department in which the research was undertaken.

Female Genital Mutilation (FGM) is used to describe procedures involving injury to, or partial or total removal of the external female genitalia for non-medical reasons; ranging from Type II through to Type IV (World Health Organisation (WHO), 2008). An estimated 66,000 women in the UK live with the consequences of FGM and approximately 1-2 new cases a week are seen in Liverpool Women's NHS Foundation Trust maternity services.

The physical consequences of FGM are well documented and include bleeding, pain, scarring, reproductive, urinary and genital infections, childbirth complications and death (WHO, 2000). The limited research suggests some women with FGM may also be at an increased risk of anxiety, depression or post-traumatic stress, and may also experience feelings of shame, guilt and loss, which can impact on their relationships with others and their self-confidence (see Chapter One, Literature Review).

Pregnancy, for all women, is a time of transition which requires both physical and emotional changes; guidance documents recommend that professionals caring for women during the perinatal period are familiar with these changes (Department for Education and Skills, 2004). The physical consequences of FGM can present additional complications in pregnancy and childbirth including the need for FGM reversals in pregnancy, difficulties in monitoring labour and tears, all of which may leave women psychologically vulnerable.

The limited research suggests women with FGM may experience anxiety during physical examinations, and fear and worry over labour and the possibility of caesarean sections. Research, however, has largely been conducted outside of the UK, where maternity services differ, or was conducted long after women gave birth, so accounts may be unreliable. Prior to the current study,

there was no research examining the psychological and emotional needs of women with FGM during pregnancy in the UK.

The study explored the experience of FGM and pregnancy (including the psychological and emotional needs) in women accessing maternity services. Seven women with FGM were interviewed during their pregnancy. The interviews were recorded and then transcribed. The transcripts were analysed using Thematic Analysis (Braun & Clarke, 2006). From the analysis five themes emerged: the shame of FGM; suffering; women with FGM need to feel cared for; information sharing and specialised/individual care.

Shame and suffering were particularly pertinent themes for participants. Most had experienced pressure to undergo FGM to avoid feelings of shame. For one lady, her move to the UK meant she had experienced shame *because* of her FGM and feeling different from women. In addition to shame, most also described mixed feelings about their FGM, highlighting the complex nature of the psychological processes involved in adjusting to FGM. The ongoing physical consequences experienced by some meant emotional suffering throughout their life. This gave rise to the expectation that pregnancy and labour would mean more suffering, physically and emotionally. Some feared birth and labour because of concerns about how the baby was going to fit; worries were echoed by professionals and in the experiences of others with FGM. The fear is a huge emotional burden during a very vulnerable time.

All of the women spoke positively about their experience of care at the Liverpool Women's NHS Foundation Trust Hospital. The women described *how* the care was delivered as being as important as *what* care was given. Staff members were described as kind, warm and smiling lots, which women found reassuring. Women described predictable, responsive care and a desire for consistency in their care (seeing the same midwife). Some women made positive comparisons between the care here and back home, which was also reassuring.

The knowledge and experience of professionals caring for women with FGM was very important. For some, a lack of knowledge was synonymous with poor care. The women wanted professionals to demonstrate their experience by sharing information and giving examples of the care of others with FGM. Shame may inhibit women's openness about their FGM; however, it was evident that women wanted to be asked about their FGM and that those with previous experiences of birth wanted to be asked about those experiences. In asking about FGM, professionals may open up communication with women and give them a sense of empowerment and control.

Participants experienced physical examinations and reversals as necessary. Reassurance and detailed explanations were essential in managing potential anxiety related to these procedures. Language was the most common barrier to care reported by participants; the consistent use of interpreters and information in their own language were essential. Shame was also highlighted as a potential barrier.

The study has significantly contributed to the understanding of women's experience of FGM and pregnancy and may have implications for future care delivery. Women responded to a sensitive, open and non-judgemental conversation about their FGM experiences and its consequences and conversely may experience shame if professionals shy away from talking about FGM. The study highlighted the need for well trained professionals working in specialist FGM related services for pregnancy and labour.

Research Proposal

Provisional Title

An exploratory study of the experiences and views of maternity care professionals caring for women with FGM.

General Background

Female Genital Mutilation (FGM) describes the procedures involving injury to or partial or total removal of the external female genitalia, classified from Type I through to Type IV (WHO, 2008). The physical consequences of FGM may present complications in pregnancy and childbirth including the need for reversals in pregnancy and difficulties in monitoring labour and tears, all of which may leave women psychologically vulnerable. A recent study with pregnant women with FGM indicated women may experience physical and emotional suffering during pregnancy and may be vulnerable to feelings of shame, sometimes in response to others. Participants suggested that women with FGM need extra care in pregnancy; the approach of professionals providing their care was as important as types of care delivered (see Chapter One, Literature Review). This indicates that the knowledge, experience and confidence of professionals in maternity services may be particularly pertinent; however, most research has been conducted outside of the UK, or has focused on auditing quantitative outcome data.

Brief account of relevant literature

Current UK based research has focused on the auditing the care received against trust or national guidelines (Paliwal, Ali, Bradshaw, Hughes & Jolly, 2014). Evidence suggests there are major deficits in identifying and managing FGM and following through with safeguarding procedures in UK health services (Zenner, Liao, Richens & Creighton, 2013); the reasons for the deficits have not been explored. One UK based study explored the experiences of healthcare workers providing maternity care for women with FGM (Straus, McEwen & Hussein, 2009) and highlighted the need for

consistency and for professionals to be knowledgeable and skilled in managing FGM. Only Somalian-trained healthcare workers were included, thus findings may not represent the views of UK-trained healthcare workers.

Research conducted with midwives in Somalia, where FGM is common, indicated the work of the midwives is viewed as subverting Somalia culture because of the perception that FGM is culturally important (Isman, Warsame, Johansson, Fried & Berggren, 2013). Widmark, Leval, Tishelman and Alhberg (2010) found Swedish doctors working with women with FGM experienced dilemmas in providing care through wanting to remain culturally sensitive but having to re-open FGM scarring. This indicates that medical decisions involve a technical *and* emotional component and therefore it may be important to explore whether staff in the UK experience similar dilemmas.

Johansen (2006) found that perceptions of healthcare workers of FGM and efforts to be culturally sensitive meant they did not engage in conversations about FGM. Healthcare workers also reported negative personal emotions around FGM and stigmatising beliefs which created an emotional detachment, so care was delivered in a typified way. The study highlighted the need to understand the feelings, beliefs and experiences of health care professionals caring for women with FGM, because this may impact on care quality.

Aim

To explore the experiences and views of the maternity staff caring for women with FGM during pregnancy and childbirth.

Objectives/Research Questions

1. To explore the attitudes and perceptions of maternity staff in relation to FGM, including personal feelings towards FGM
2. How do the maternity staff members manage their personal feelings about FGM during care?
3. How do maternity staff members experience the women with FGM who they care for?

4. How confident do maternity staff members feel about talking to women about and managing FGM in pregnancy and labour?
5. What do maternity staff members feel that they need to know to care for women with FGM?

Design

Thematic Analysis (Braun and Clarke, 2006) will be used to explore the experiences maternity care staff providing care for women with FGM during pregnancy and children.

Participants and Sampling

Staff would be recruited from within the maternity services, at the LWH. Inclusion criteria: participants would need direct personal experiences of caring for women with FGM during pregnancy *and* labour. Staff would be excluded if they are currently under formal investigation or suspension. A sample of 10-12 participants will be used, to allow for rich examination of similarity and difference across the sample.

Procedure

Potential participants will be given an information sheet and assurances will be made that participation will not affect their working conditions. Potential participants will be offered a meeting with the researcher to discuss the study and ask questions; meetings will be held outside of the maternity department to ensure anonymity and confidentiality. It will be emphasised that colleagues or managers will not have access to transcripts or interview recordings.

If potential participants give informed consent, data will be collected during the same meeting, using semi-structured interviews, lasting approximately 60-90 minutes. The interview guide will be developed with reference to the research topic. The guide will be piloted with two participants; if no changes are made the scripts will be included in the final analysis. Participants will control the pace of and level of detail within the interview; if distressing issues are raised, participants will be offered breaks and de-briefing information. The researcher will record and transcribe the interviews.

Participants will have the right to withdraw, until the data is anonymised. Participants will be offered a meeting with the researcher to discuss and validate the themes.

Inductive Thematic Analysis (Braun & Clarke, 2006) means that the themes are data driven; this is useful for under-researched areas (as with current research topic). The approach goes beyond basic descriptions and measuring the frequency of themes (akin to content analysis). The researcher will engage in active reflection, to understand the impact of their own conceptions on the analysis. Braun and Clarke (2006) outline the process for Thematic Analysis: Stage 1: Familiarisation with the data; Stage 2: Generating initial codes; Stage 3: Searching for themes - considering how different codes might combine to form overarching themes; Stage 4: Reviewing the themes - the relationship between codes and themes (overarching and sub) will be considered; including how different themes tell the story of the data; Stage 5: Defining and naming themes - identifying the essence, scope and content of each theme; Stage 6: Producing the final account with direct quotes and visual map.

References

Benedict, R. (1946). In Wong, Y. & Tsai, J. (2007). Chapter 12: Cultural models of shame and guilt. In Tracy, J.L., Robin, R.W., & Tangney, J.P. (2007). *The self-conscious emotions: Theory and research*. New York: Guildford Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Department for Education and Skills. (2004). *National service framework for children, young people and maternity services.* London: HMSO.

Isman, E., Warsame, A.M., Johansson, A., Fried, S., & Berggren, V. (2013). Midwives' experiences in providing care and counselling to women with female genital mutilation (FGM) related problems. *Obstetrics and Gynaecology International, 2013*, 1-9.

Johansen, R.E.B. (2006). Care for infibulated women giving birth in Norway: An anthropological analysis of health worker's management of a medically and culturally unfamiliar issue. *Medical Anthropology Quarterly, 20*(4), 516-544.

Lewis, .H.B. (1974). *Shame and guilt in neurosis*. Oxford, UK: International Universities Press.

Mehta, N. (2011). Mind-body dualism: A critique from a health perspective. *Mens Sana Monographs, 9*(1), 202-209.

Paliwal, P., Ali, S., Bradshaw, S., Hughes, A., & Jolly, K. (2013). Management of type III female genital mutilation in Birmingham, UK: A retrospective audit. *Midwifery, 30*, 282-288.

Straus, L., McEwen, A., & Hussein, F.M. (2007). Somali women's experience of childbirth in the UK: Perspectives from Somali health workers. *Midwifery, 25*, 181-186.

Widmark, C., Leval, A., Tishelman, C., & Ahlberg, B.M. (2010). Obstetric care at the intersection of science and culture: Swedish doctors' perspective on obstetric care of women who have undergone female genital cutting. *Journal of Obstetrics and Gynaecology, 30*(6), 553-558.

Wong, Y. & Tsai, J. (2007). Chapter 12: Cultural models of shame and guilt. In Tracy, J.L., Robin, R.W., & Tangney, J.P. (2007). *The self-conscious emotions: Theory and research*. New York: Guildford Press.

World Health Organisation (2000). *A systematic review of the health complications of female genital mutilation including sequelae in Childbirth.* Geneva, Switzerland: World Health Organisation. Retrieved from http://www.who.int/gender/other_health/en/systreviewFGM.pdf

World Health Organization. (2008) *Female Genital Mutilation. Fact Sheet Number 241.* www.who.int/mediacentre/factsheets/fs241/en/ (Last accessed: December 27 2014).

Zenner, N., Liao , L.M., Richens, Y., & Creighton, S.M. Quality of obstetric and midwifery care for pregnant women who have undergone female genital mutilation. *Journal of Obstetrics and Gynaecology*, *33*, 459-462.